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ABSTRACT

A summary of proceedings of the Forum on Arthritis Research and Education in Nursing and Allied Health is presented. The keynote address, "The Burden of Arthritis," by Dorothy P. Rice, provides data collected by the National Center for Health Statistics on the prevalence of arthritis, the burden it imposes, and the volume, type, and cost of health services utilized by arthritis patients. Information on the preparation of the generalist clinician to provide services for arthritis patients is presented based on a mail survey of U.S. and Canada nursing, occupational, and physical therapy undergraduate programs. Recommendations are offered concerning curriculum content for basic professional programs, basic educational methods and resources, faculty preparation to teach arthritis content, and continuing education for the generalist. Information about graduate level specialist preparation and recommendations concerning specialist preparation, resources and programs, and public and patient education are presented. Recommendations are also given concerning research needs in arthritis, suggested research funding, research settings, and topics for studies. Bibliographies on numerous topics concerning arthritis, psychosocial support for patients, patient education materials, and professional preparation are included. Information on federal funding for advanced training and research for nurses and allied health professionals is included. (SW)

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Arthritis Research & Education in Nursing & Allied Health



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PREFACE

In April, 1976, after more than a year of careful study, the National Commission on Arthritis and Related Musculoskeletal Diseases submitted its final report to the Congress. This report, entitled Arthritis: Out of the Maze, contained over 150 recommendations for urgently needed action in specific areas. Collectively these recommendations comprise the "Arthritis Plan." In October, 1976, passage of P.L. 94-562 officially established the National Arthritis Advisory Board (NAAB) and gave it a mandate to review and evaluate implementation of the Arthritis Plan. In addition, the Board was authorized to make recommendations concerning the Plan to the Congress, the Secretary of Health, Education, and Welfare and the heads of other appropriate Federal agencies with respect to guidelines, policies, and procedures of Federal programs relating to arthritis.

In carrying out its charge, the NAAB has sought information and ideas from a variety of sources. This forum represents an important step in that process. A number of the recommendations in the Plan concern research and education in nursing and allied health; the services provided by clinicians in these fields represent a major component of total care for many arthritis patients; and the total annual cost of these services is substantial. Therefore, the NAAB convened this invitational conference of outstanding experts in nursing, physical therapy, and occupational therapy to assist it in assessing the current state of the art and needs for future action in arthritis related research and education in their fields.

To put this discussion in practical perspective, the NAAB invited Dorothy P. Rice, Director of the National Center for Health Statistics, to open the forum by sharing data collected by the center on the prevalence of arthritis, the burden it imposes on its victims and on society, and on the volume, type, and cost of health services utilized by arthritis patients. Mrs. Rice's keynote address made it clear that arthritis is one of this Nation's major health problems and that nursing and allied health professionals are extensively involved in care of arthritis patients. In this context, an obvious and urgent need exists to identify and correct any significant deficiencies in the preparation of nurses and therapists and to validate the effectiveness of the clinical services they provide to arthritis patients.

Consideration of these issues during the forum was organized around six state-of-the-art papers, each followed by nearly an hour of vigorous and far-ranging discussion by the participants. Topics for these papers were chosen to focus discussion on areas of broad concern to the NAAB and on topics addressed in the Arthritis Plan. They included:

EDUCATION

Preparation of the Generalist Clinician to Provide Services for Arthritis Patients (What knowledge and skills are needed and how might

these be learned during basic professional study and continuing education?)

Consultant: Marjorie C. Becker, Ph.D., R.P.T.
Assistant Dean for Allied Health Education
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Preparation of Arthritis Specialists (Skills and knowledge needed by clinicians and teachers specializing in arthritis care, and how these might be learned through graduate and continuing education)

Consultant: Joan Sutton, R.N., M.S.N.
Instructor in Medicine
Johns Hopkins University School of Medicine

Preparation to Work in an Arthritis Care "Team" (Skills and knowledge needed for nursing and allied health clinical specialists in arthritis care to work with one another and with physician specialists on the arthritis team and to fulfill responsibilities as consultants to primary care physicians and generalist clinicians in their own disciplines; how these skills might be learned)

Consultant: Janice Smith Pigg, R.N., B.S.N.
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RESEARCH

Kinesiological, Kinematic, and Biomechanical Studies of Gait (and other functional movement and the application of these techniques to arthritis care)

Consultant: Helen Hislop, Ph.D., R.P.T.
Professor and Chairman
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University of Southern California

Relief of Pain Through Use of Physical Modalities (including such techniques as joint mobilization, acupressure, transcutaneous nerve stimulation, and biofeedback as well as more traditional methods such as heat, cold, and massage)

Consultant: Steven L. Wolf, Ph.D., R.P.T.
Associate Professor
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Dealing with Uncertainty: The Need to Provide Psychosocial Support
and Assist Persons With Arthritis to Change Their Lifestyles

Consultant: Elizabeth Yerxa, Ed.D., O.T.R.
Chairperson
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To provide both broad expertise and varying points of view, invited participants were selected to represent three communities of interest:

- ° Clinicians specializing in arthritis care
- ° Faculty of undergraduate and graduate educational programs in nursing and allied health
- ° Clinical investigators whose research has special relevance to the problems of arthritic patients.

Because of the overlapping roles of nurses and allied health professionals in caring for arthritis patients, the forum was planned as an interdisciplinary venture. However, in order to provide useful depth and focus during discussions, a decision was made--reluctantly--to select allied health participants from only two disciplines: occupational and physical therapy. Fortunately, professionals from several other fields, such as rehabilitation counseling and social work, attended as observers. Their contributions helped greatly to direct attention to questions of interest to the full arthritis care team.

Recognizing that proposals for improvement of training and research in the areas of arthritis cannot be considered sensibly in isolation, some of the participants were selected principally for their broad knowledge of a major area of research, or their familiarity with current trends and issues in professional education rather than to provide expertise in arthritis.

Participants also included representatives from a variety of federal agencies whose programs include potential support for advanced training and/or research in nursing and allied health. These agency representatives were asked to share information about their agencies' current programs, and to comment on the feasibility of implementing actions suggested by participants within the scope of authority and resources of their agency.

Finally, a number of private foundations interested in arthritis were invited to send observers to the forum as were each of the Multipurpose Arthritis Centers currently supported by the National Institute of Arthritis, Metabolism, and Digestive Diseases. A high proportion of the centers were represented, and their staff members contributed extensively to the discussions.

In preparation for the forum, participants were asked to review the Arthritis Plan, giving particular attention to those recommendations that

concerned research and education in nursing and allied health. They were also asked to bring to the forum their written comments on any or all of the following five questions.

1. How fully do you believe the recommendations in the Arthritis Plan related to research and education in nursing and allied health have been implemented?
2. Can you cite specific examples of educational programs/research projects related to this topic which you feel are particularly valuable or interesting?
3. Should the recommendations in the Arthritis Plan related to this topic be revised or expanded in any way? If so, how?
4. What aspects of implementation should have highest priority during the next 5 years?
5. What actions would you suggest the National Arthritis Advisory Board recommend to the Congress, the Secretary of Health, Education, and Welfare, and to other Federal agencies?

These questions provided the framework for each of the state-of-the-art papers and for the discussions that followed.

These proceedings are a highly condensed summary of the major points raised during those discussions, and of the information and ideas contained in the six state-of-the-art papers, the keynote address, and in the valuable written submissions prepared by the participants.

In selecting and organizing material to be included in these proceedings, this wealth of information has been treated in the way that makes it most useful to the National Arthritis Advisory Board. Therefore, primary emphasis has been placed on the various needs for future action identified during the forum. No effort was made to reach formal consensus on recommendations; however, in most cases the suggestions included in the proceedings were made by several participants and appeared to be generally regarded as worthwhile by the full group. In those cases where disagreement or reservations were expressed, an effort has been made to reflect them in this summary.

As the proceedings go to press, work has already begun on several projects suggested during the forum. For example, surveys of Federal legislation providing funding for advanced training and for research in nursing and allied health, have been completed in time to include a summary of findings as appendices to the proceedings.

A condensed summary such as this cannot hope to capture the full range of useful information and thought-provoking comments brought forth during 2 days of lively discussion by such able participants. However, these proceedings provide an important stimulus and guide to the National Arthritis

Advisory Board in its future work and should serve a similar purpose for the educational and research communities in nursing and allied health, for this forum served both to reaffirm the purpose of the Arthritis Plan and to define new ways in which that purpose can be accomplished.

Nancy T. Watts, Ph.D., R.P.T.
Chairman, Forum Planning Committee

ACKNOWLEDGMENTS

This forum has benefitted from the work of many people, particularly those on the staff of the National Arthritis Advisory Board and the National Institute of Arthritis, Metabolism, and Digestive Diseases. In addition, the planning committee wishes to thank Hannah Gruen, Janice Pigg, Joan Sutton, and David Wayne Smith of the executive committee of the arthritis health professionals section of the Arthritis Foundation who helped plan the focus of the forum and suggested many potential participants.

MANUSCRIPT NOTE

This summary of proceedings of the Forum on Arthritis Research and Education in Nursing and Allied Health is based on the verbatim transcript of the 2-day meeting, on papers and bibliographies by the six state-of-art presenters, and on the written comments and recommendations submitted by invited participants. The summary necessarily omits or skims over many of the interesting comments and condenses others in order to make this brief enough for easy reference. The presentations and discussions have been organized around background and rationale for groups of recommendations made both orally and in writing by forum presenters and participants for consideration by the National Arthritis Advisory Board.

Cynthia Snow
Manuscript Editor

KEYNOTE ADDRESS: THE BURDEN OF ARTHRITIS

Dorothy P. Rice, Director
National Center for Health Statistics

I am very pleased and flattered to have been asked to give the keynote address for this Forum on Needs for Arthritis Related Research and Education in Nursing and Allied Health. I have great admiration for the important services provided by nurses, occupational therapists, physical therapists, and other allied health professionals. I am especially aware of the need for expanded educational programs to prepare nursing and allied health clinicians to provide service as well as the need for expanded research to test the effectiveness of present methods of care.

Arthritis and rheumatism are among the most common of the chronic diseases affecting the American people. Like many chronic diseases, these are managed or controlled rather than cured and may affect victims for decades, impairing function and requiring medical care. At its worst, arthritis can cause great pain, deformity of limbs, and even early death. Pain and crippling may make an arthritic patient unemployable, interfere with usual household duties and routines, and create a physical, emotional, and economic burden for the arthritis sufferer and his or her family.

The National Center for Health Statistics is a unique resource for the collection and dissemination of data on the health of the Nation. Data from the center indicate the burden that arthritis represents for its victims and for society. I will emphasize particularly data that reflect what we know about the effect of arthritis on the individual's life and the use of health care services and then will briefly review economic costs of this disease. Data from a variety of surveys are presented to show the kinds of information that are available. In a way, I am here to show that data on arthritis are available, despite what one often hears to the contrary.

The National Center for Health Statistics has the responsibility for the collection and dissemination of statistics on the health of the Nation. In the performance of that function, it conducts a variety of national sample surveys, and the data presented here are drawn from such surveys.

The Health and Nutrition Examination Survey (HANES) is an important source of data on arthritis, based on tests, X-rays, and physical evaluation of samples of the civilian, noninstitutional population. It takes several years for mobile units to travel around the country and to interview and examine the population, so there is a series of surveys, and data are presented from 1960-62 and 1971-75.

Results of X-rays taken in health examination surveys of 1960-62 led to an estimate of the prevalence for osteoarthritis affecting the hands or the feet of 40.5 million persons or 37.7 per 100 adults aged 18-79. Nearly one-fourth of the people with osteoarthritis had moderate

or severe forms of this condition. The rate increased steadily with advancing age for both men and women. By age 79, 81 out of 100 men and 90 out of 100 women had osteoarthritis. These data underestimate the total prevalence of osteoarthritis because they deal only with the hands and feet, which are, however, two of the most common anatomical sites for such degenerative changes.

The prevalence estimate for rheumatoid arthritis in the 1960-62 HANES was 3.6 million adults or 3.2 per 100 adults, based on X-ray and serological evidence. Nearly one-third of these people had the most severe (classical or definite) forms of rheumatoid arthritis. The prevalence of both types of the more severe forms of arthritis was greater among women than among men and increased rapidly with age. For example, the rates for all types of rheumatoid arthritis increased to 14.1 per 100 men and to 23.5 per 100 women aged 75-79; for classical and definite arthritis, the rates were 8.2 per 100 for men and 6.2 per 100 for women.

The 1971-75 HANES prevalence estimates for arthritis were 3.8 per 100 adults aged 25-74 based on X-rays, and nearly one-quarter of these adults had moderate or severe conditions. The prevalence rates for moderate or severe conditions increased with age from essentially none among young adults to 4.6 per 100 adults aged 65-74.

The HANES of 1971-75 supplies supplementary data from an in-depth medical history of symptoms, injuries, treatment received, effectiveness of treatment, and limitation of function. Similar information was obtained in the HANES II completed in February 1980. This survey included X-rays of the lumbar and cervical spine. These are being read for osteoarthritis and will be available in publications and public use data tapes for researchers.

The 1971-75 HANES also included a nutrition examination of all participants and a more detailed health examination for a subset of adults 25-74 years of age. An arthritis history was taken for those people in the detailed sample who had indicated that they had pain, aching, swelling, or stiffness in any of their joints for at least a month or that they had a history of arthritis or gout.

Table 1 shows that nearly one-quarter of the adults aged 25-74 had mild joint trouble at some time; 7 percent, moderate trouble; and 2 percent, severe trouble. For each degree of severity, prevalence tended to increase with age. According to the arthritis history, nearly 7 percent of adults 25-74 years of age were currently being treated by selected practitioners for joint trouble; about half of them were being treated by a general practitioner.

Table 2 shows the percent of the population 25-74 years of age ever treated by selected practitioners for joint troubles. The general practitioner was the most frequently reported source of care. About 8 percent had seen an orthopedist at some time; 5 percent, a chiropractor; and 2 percent had been treated by a physical therapist.

TABLE 1. Estimated Percent of the U.S. Population Ages 25-74 Years Ever Having Mild, Moderate or Severe Joint Trouble, by Sex, Race, and Age: HANES, 1971-1975

Reported condition of joint trouble	Total	Sex		Race		Age in years				
		Male	Female	White	Black	25-34	35-44	45-54	55-64	65-74
Percent of Population										
Mild	24.2	23.4	25.0	25.0	18.8	15.9	23.7	26.8	28.4	32.5
Moderate	7.0	6.0	7.8	7.1	6.1	3.0	6.0	8.8	8.9	10.9
Severe	2.2	1.9	2.5	2.0	4.1	0.6	1.7	2.2	4.4	3.3

TABLE 2. Estimated Percent of U.S. Population Ages 25-74 Ever Having Been Treated by Selected Practitioners for Joint Trouble, by Sex, Race, and Age: HANES, 1971-1975

Practitioner	Total	Sex		Race		Age in years				
		Male	Female	White	Black	25-34	35-44	45-54	55-64	65-74
Percent of Population										
General practitioner	15.8	13.7	17.6	16.1	13.6	9.4	12.5	17.4	22.4	22.4
Internist	2.4	1.7	2.9	2.5	1.5	0.7	1.5	3.5	3.4	3.6
Rheumatologist	0.6	0.4	0.7	0.6	0.2	0.1	0.4	0.9	0.8	0.8
Orthopedist	8.0	8.4	7.7	8.5	4.6	5.0	9.9	9.5	9.2	6.7
Chiropractor	4.7	4.8	4.7	5.2	1.2	2.2	4.5	5.4	6.5	6.7
Osteopath	2.2	2.1	2.3	2.5	0.2	1.0	1.5	2.4	4.0	3.0
Foot Doctor	0.7	0.5	0.8	0.7	0.3	0.4	0.2	0.8	1.3	0.8
Physical Therapist	2.2	2.3	2.1	2.3	1.3	1.1	2.7	2.4	3.1	2.0
Occupational Therapist	0.1	0.1	0.0	0.1	0.0		0.1		0.0	0.4
Other	2.5	2.9	2.1	2.6	1.7	1.7	2.4	2.8	3.0	2.8

NOTE: These tables are based on the Arthritis History Supplement which was given only to those in the detailed sample who had indicated that they had pain, aching, swelling, or stiffness in any of their joints for at least 1 month or had indicated that they had a history of arthritis or gout. All of those not asked to respond to the Arthritis History Supplement are assumed to have had no history of significant joint problems.

Table 3 shows selected treatments and the patients' opinions of their effectiveness. Generally, at least two out of three people found a particular treatment helpful. It is interesting to note that 14 percent of the adults used aspirin and more than 80 percent of them thought this treatment was helpful. The next most used treatment was hot-pack or heating pad, with 12 percent using this form of treatment and 84 percent of them indicating that it was helpful.

Table 4 shows the percent of the population unable to perform various activities without help from someone else or without the help of some special device. This table covers limitations of function resulting from all disorders, not just arthritis. 1.7 percent cannot go up or down stairs without help; 1.5 cannot dress themselves without help. Again, these percentages rise with age.

The HANES I data I have just discussed have been published.¹ Some additional work on HANES I data is in preparation and include several kinds of analyses:

1. The relationship of selected symptoms of joint disease such as pain on movement, swelling, and limitation of motion in the lower back, hip, or knee from history and standardized physical examinations with X-ray evidence of osteoarthritis and osteoporosis.
2. The relationship of symptoms of joint disease, X-ray evidence, bone density, cortical thickness measures from X-ray, and serum calcium and phosphorus levels.
3. The extent of disability and apparent effectiveness of various types of treatments with various grades of osteoarthritis and other types of joint conditions.

From the HANES II examination just completed, X-rays of the lumbar and cervical spine are being read for osteoarthritis and osteoporosis. The relationship of these X-ray findings and the selected symptoms from history and from examination will also be analyzed and published as well as the findings with respect to the extent of disability and percentage effectiveness of various treatments. Single copies of reports will be available for the asking.²

Table 5 moves to data from the Health Interview Survey. This is another continuing survey of some 40,000 households a year in which people are asked about their health status. This survey provides a broad picture of the prevalence and impact of chronic diseases and shows the impacts, the "burdens," of these diseases. Arthritis has the highest prevalence of these diseases--24 million cases. The prevalence of arthritis is 113 per 1,000 persons. Of the people with arthritis, about 70 percent report some or a great deal of bother, pain or discomfort.

About 45 percent of those with arthritis had had medical attention in the past year, and slightly over one-third (36 percent) were currently

TABLE 3. Estimated Percent of U.S. Population Ages 25-74 Years, by Use and Effectiveness of Selected Types of Treatments for Joint Trouble, HANES, 1971-1975

Type of treatment for joint trouble	Treatment Used	Do Treatments Help?	
		Yes	No
	Percent of Population		
Splints	2.1	1.9	0.2
Braces	3.2	2.4	0.7
Diathermy or paraffin	2.1	1.7	0.4
Hot pack or heating pad	11.8	10.0	1.8
Cold pack or ice	1.4	1.1	0.3
Rest	9.6	8.6	1.1
Traction	3.4	2.6	0.8
Exercise or physical therapy	6.8	5.8	1.0
Aspirin	13.9	11.6	2.3
Cane	1.5	1.4	0.1
Crutch	1.8	1.7	0.1
Stiff mattress	6.4	5.5	0.8
Bedboard	4.3	3.6	0.7
Injectons into any joints	7.0	5.9	1.1
Cortisone-like medicine by mouth	2.6	1.9	0.8
Butazolidin	1.0	0.8	0.2
Darvon or Tylenol	5.1	3.7	1.4
Indocin	2.0	1.4	0.6

NOTE: This table is based on the Arthritis History Supplement which was given only to those in the detailed sample who had indicated that they had pain, aching, swelling, or stiffness of their joints for at least 1 month or had indicated that they had a history of arthritis or gout. All of those asked to respond to the Arthritis History Supplement are assumed to have had no history of significant joint problems.

TABLE 4. Estimated Percent of U.S. Population Ages 25-74 Years Unable to Perform Various Activities Without the Help of Someone Else or the Help of Some Special Device, by Sex, Race, and Age: HANES 1971-1975

Activity Requiring Assistance	Total	Sex		Race		Age in Years				
		Male	Female	White	Black	25-34	35-44	45-54	55-64	65-74
Percent of Population										
Go up or down stairs	1.7	1.6	1.8	1.8	0.9	1.1	1.7	1.7	1.3	3.7
Get into or out of car	1.6	1.4	1.7	1.6	0.7	1.1	1.5	1.3	1.4	3.5
Use washing facilities	1.4	1.4	1.4	1.5	0.3	1.0	1.4	1.4	1.2	2.5
Dress self	1.5	1.5	1.5	1.6	0.3	1.0	1.4	1.5	1.5	2.4
Feed self	1.3	1.3	1.3	1.4	0.3	1.0	1.4	1.3	1.1	2.3
Get into or out of bed	1.4	1.4	1.4	1.4	0.4	1.0	1.4	1.3	1.1	2.4

NOTE: This table is based on the Arthritis History Supplement which was given to those in the detailed sample who had indicated that they had pain, aching, swelling, or stiffness in any of their joints for at least 1 month or had indicated that they had a history of arthritis or gout. All of those not asked to respond to the Arthritis History Supplement are assumed to have had no history of significant joint problems.

TABLE 5. Impact of Selected Chronic Conditions, United States, from the Health Interview Survey, 1978

Condition	Prevalence	Causing Limitation of Activity	Medical Attention in Past Year	Number of Bed Days Per Year	Bothered a Great Deal or Some	Now Under Treatment or Medication Recommended by Doctor
Number in Thousands						
All heart conditions	13,441	5,630	9,497	130,191	6,061	7,543
Coronary heart	3,929	2,295	3,263	61,130	2,369	3,072
Arthritis	24,241	5,084	11,372	94,851	17,744	8,700
Back problems	9,768	2,531	3,488	33,546	7,378	1,707
Diabetes	5,193	1,610	4,191	44,354	1,791	3,602
Hypertension w/o heart	18,765	1,737	13,920	16,421	4,857	11,923
Asthma	6,035	1,442	3,818	36,785	4,943	3,317
Stroke (Cerebrovascular)	1,714	694	1,150	21,018	878	962
Emphysema	2,068	917	1,265	25,632	1,346	749
Hernia	4,048	631	2,263	22,877	2,293	916
Ulcer	3,774	507	2,293	23,954	2,779	2,225
Bronchitis	7,064	285	4,863	14,895	5,414	1,552
Hay fever	15,516	337	5,774	7,811	12,235	4,681
Sinusitis	22,545	121	7,411	11,194	17,831	4,569
Hemorrhoids	9,213	82	2,610	6,369	5,753	1,413

NOTE: Data for 1978 based on a one-sixth subsample of households.

under treatment or medication recommended by a physician. However, only about 20 percent of the people with arthritis were limited in activity because of their arthritis. "Limitation of activity" is a term that encompasses limitations ranging from inability to work to much lesser restrictions on social and civic activities. One might infer from these data that people with arthritis somehow learn to cope and carry on in spite of their arthritis. This table is worth studying because it indicates the impact of different conditions and permits interesting comparisons.

The use of health services is shown in table 6, which is derived from another survey, the National Ambulatory Medical Care Survey (NAMCS). Office visits for arthritis and rheumatism totaled 15.6 million in 1978, representing 3 percent of all visits to office-based physicians. This survey does not include visits to outpatient departments, to clinics, and to other organized services. About 8 out of 10 visits for arthritis and rheumatism were made to physicians in primary care, that is, physicians in general and family practice and in internal medicine.

Table 7--also from the National Ambulatory Medical Care Survey--shows the chronic and recurrent nature of arthritis and rheumatism. Of all the visits for arthritis and rheumatism, 7 out of every 10 are return visits by a patient who has seen the doctor before for arthritis. The three therapeutic services most frequently rendered in office visits for arthritis and rheumatism--as reported by physicians--are drugs, medical counseling and physical therapy. Physical therapy was provided or prescribed in 14 percent of the visits for arthritis and rheumatism; medical counseling in 23 percent; and drugs (prescription and non-prescription) were ordered in 77 percent of the visits. In a majority of visits, the arthritis patient is instructed to return at a specific time. Referrals and hospitalizations occur infrequently.

Additional information from the NAMCS shows that it is a complaint or a symptom related to the musculoskeletal system that prompts these visits. These symptoms are later diagnosed as arthritis or rheumatism, and in nearly 60 percent of these visits, the doctor reports no other diagnosis in connection with the visit. Obesity is a condition that frequently occurs with the conditions of arthritis and rheumatism.

Data from the Health Interview Survey are shown in table 8--the survey of households. The data presented here include office visits, telephone calls and other sources of ambulatory care in clinics, outpatient departments and other organized settings. In 1975, a total of 853 million visits was reported. More than half are visits for chronic conditions, of which 34 million are for arthritis and rheumatism. Visits for arthritis, rheumatism and gout represented 1 percent of all visits at ages under 45, but nearly 12 percent of the visits by persons 65 and over.

The rates of physician services also increase with age for all chronic conditions. The increase is especially large for arthritis, rheumatism and gout, from 3.8 visits per 100 persons under age 45 to 65.7 visits per 100 persons aged 65 and over.

TABLE 6. Office Visits for Arthritis and Rheumatism by Physician Specialty, United States, 1978

Physician Characteristic	Number of Visits in Thousands	Percent of Visits
All Visits*	15,572	
<u>Physician Specialty</u>		
General and Family Practice	8,102	52.0
Internal Medicine	3,957	25.4
Surgical Specialties	2,680	17.2

*Based on estimated total of 584.5 million visits to office-based physicians.

TABLE 7. Percent Distribution of Office Visits for Arthritis and Rheumatism, by Status of Visit, United States, 1978

Visit Status	Percent of Visits
New Patient	10.0
Old Patient	90.0
New Problem	19.9
Old Problem	70.1

SOURCE: National Center for Health Statistics, National Ambulatory Medical Care Survey.

TABLE 8. Physician Visits for Diagnosis and Treatment and Percent Distributions, According to Condition Causing Visit, by Age and Sex, 1975

Condition Causing Visit	Total	Age			Sex	
		Under 45 Years	45-64 Years	65 years and over	Male	Female
Number of visits in thousands						
All conditions	853,086	519,460	209,446	124,180	364,362	488,724
Percent of All Conditions						
All conditions	100.0	100.0	100.0	100.0	100.0	100.0
Chronic conditions	52.1	40.5	67.5	74.5	50.0	53.6
Arthritis, rheumatism, gout*	4.0	1.1	6.9	11.5	3.4	4.4
Other chronic conditions	48.0	39.4	60.6	63.0	46.5	49.2
Acute conditions	44.9	57.1	28.9	20.5	47.5	43.0
Chronic and acute conditions**	3.1	2.4	3.6	5.0	2.6	3.4

*Includes all visits listing arthritis, rheumatism or gout. Other chronic or acute conditions may also be listed for these visits.

**Includes all visits which have both a chronic and an acute condition listed for the visit.

SOURCE: Health Interview Survey, National Center for Health Statistics.

The National Hospital Discharge Survey obtained data on hospitalization from a sample of hospitals and a sample of patients in the sample hospitals. Table 9 shows data on discharges in 1977, and table 10 gives data on days of care. Chronic and acute diseases each account for about 50 percent of the discharges, but owing to the longer average length of stay, chronic diseases accounted for 59 percent of the days compared to 41 percent for acute diseases.

The shift in relative importance from acute to chronic diseases as age increases is clearly seen in the changing percent distribution for discharges and the days of care shown in table 9 and 10. Whereas almost two-thirds of the discharges under 45 years of age were for acute diseases in 1977, the ratio was reversed at 65 years and over, with two-thirds of the discharges being for chronic disease. A similar but less drastic shift also occurs for days of care.

Arthritis, rheumatism and gout accounted for about 2 percent of all the discharges and 6 million days of care out of a total of 262 million days of care.

Another survey, the National Nursing Home Survey, is based on a sample of nursing homes and a sample of the patients in those homes. A total of 1.3 million residents was reported in nursing homes in 1977. The nursing home population is predominantly white, female, and very old. In 1977, 70 percent of nursing home residents were female and less than 10 percent were under age 65. Arthritis or rheumatism was the primary diagnosis at last medical examination for 4 percent of the residents (56,000 persons), but 25 percent of the residents (320,000) reported arthritis or rheumatism as a chronic condition or impairment. In both cases, over 80 percent were women.

Current total health expenditures amount to about \$200 billion. The data for fiscal year 1975 show the estimated direct expenditures for personal health care for all diseases totaling \$99 billion. With the rate of inflation in the medical care market as well as in the general economy, the escalation has been rapid. The data for 1975 shown in table 11 show that the costs of arthritis, rheumatism and gout accounted for 2.6 percent of all direct expenditures, or \$2.5 billion. The table gives a breakdown of expenditures into hospital care, physician services and other professional services. Those other professional services include the services of nurses, physical therapists--all professionals other than physicians. Out of the total expenditure of almost \$100 billion, \$1.4 billion was spent in 1975 for "other professional services."

Within each expenditure category, arthritis, rheumatism and gout were responsible for small proportions of the total, reaching a high of 13 percent for other professional services. This becomes meaningful here because it is clear that these are the costs of services about which this forum is concerned.

The breakdown of expenditures for arthritis, rheumatism and gout shows that physician and other professional services accounted for a

TABLE 9. Discharges from Short-Stay Hospitals and Percent Distributions, According to First-Listed Diagnosis, by Age and Sex, 1977

Category of first-listed diagnosis	Total	Age			Sex	
		Under 45 Years	45-64 Years	65 Years and Over	Male	Female
Number of discharges in thousands						
All discharges	35,902	18,955	8,604	8,344	14,385	21,518
Percent of total						
All discharges	100.0	52.8	24.0	23.2	40.1	59.9
Chronic diseases	100.0	38.0	31.2	30.8	42.7	57.3
Arthritis, rheumatism, gout	100.0	22.9	41.3	35.8	38.5	61.5
Other chronic diseases	100.0	38.5	30.5	30.7	42.8	57.2
Acute Diseases	100.0	68.2	16.5	15.4	37.4	62.6

SOURCE: Hospital Discharge Survey, National Center for Health Statistics.

TABLE 10. Days of Care in Short-Stay Hospitals and Percent Distributions, According to First-Listed Diagnosis, by Age and Sex, 1977

Category of first-listed diagnosis	Total	Age			Sex	
		Under 45 Years	45-64 Years	65 Years and Over	Male	Female
Number of days in thousands						
All days of care	262,407	96,589	73,200	92,618	112,082	150,326
Percent of Total						
All days of care	100.0	36.8	27.9	35.3	42.7	57.3
Chronic diseases	100.0	28.1	31.9	40.0	44.0	56.0
Arthritis, rheumatism, gout ,	100.0	16.9	38.4	44.7	36.2	63.8
Other chronic diseases	100.0	28.6	31.6	39.8	44.3	55.7
Acute diseases	100.0	49.3	22.1	28.5	40.9	59.1

SOURCE: Hospital Discharge Survey, National Center for Health Statistics.

TABLE 11. Estimated Direct Expenditures and Percent Distributions According to Disease Category and Type of Expenditure, Fiscal Year 1975

Disease Category	Type of Expenditure						Other*
	Total	Hospital Care	Physicians' Services	Other Profes- sional Services	Drugs and Drug Sundries	Nursing Home Care	
Amount in millions							
All diseases	**\$99,373	\$46,415	\$22,100	\$ 1,453	\$10,605	\$ 9,000	\$ 9,800
Chronic diseases	56,479	28,913	10,969	1,310	5,470	7,517	2,300
Arthritis, rheumatism	2,541	814	704	183	454	386	0
Other chronic diseases	53,938	28,099	10,265	1,127	5,016	7,131	2,300
Acute diseases	42,894	17,502	11,131	143	5,135	1,483	7,500
Percent of total							
All diseases	100.0	46.7	22.2	1.5	10.7	9.1	9.9
Chronic diseases	100.0	51.2	19.4	2.3	9.7	13.3	4.1
Arthritis, rheumatism	100.0	32.0	27.7	7.2	17.9	15.2	0
Other chronic diseases	100.0	52.1	19.0	2.1	9.3	13.2	4.3
Acute diseases	100.0	40.8	26.0	0.3	12.0	3.5	17.5
Percent of all diseases							
All diseases	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Chronic diseases	56.8	62.3	49.6	90.2	51.6	83.5	23.5
Arthritis, rheumatism	2.6	1.8	3.2	12.6	4.3	4.3	0
Other chronic diseases	54.3	60.5	46.4	77.6	47.3	79.2	23.5
Acute diseases	43.2	37.7	50.4	9.8	48.4	16.5	76.5

*Includes dentists' services, eyeglasses and appliances.

**Excludes unallocated expenditures for prepayment and administration, government public health activities, other health services, research, and construction.

SOURCE: Lynn Paringer and Aviva Berk, "Costs of Illness and Disease, Fiscal Year 1975," Public Services Laboratory, Georgetown University, Washington, D.C., January 4, 1977. Expenditures for arthritis and rheumatism were estimated by the National Center for Health Statistics.

little more than one-third of the total and hospital care for about another third. Drugs and drug sundries took 18 percent of the expenditures for arthritis and rheumatism and about twice the share for other chronic diseases.

Recognition of the need for additional data on expenditures led to a National Medical Care Expenditure Survey in which 13,500 households were surveyed over a period of a year, with five interviews per household. Data from this survey will be available soon from the National Center for Health Services Research and will provide information about visits to a variety of allied health professionals including nurses, physical therapists, nurse practitioners, paramedics, home health aides, physicians' assistants, chiropractors, and foot doctors. The data will include the type of persons seen, the condition for which the visit was made, the total charges for the visit, and the sources of payment for the visit, in addition to the characteristics of the person for whom the visit was made.

Table 12 is fairly difficult to understand, but details on how the calculations of indirect costs are made are available in a variety of reports.³⁻⁵ The direct costs are those from table 11 which represent the direct expenditures for all medical services--hospitals, physicians, other health professionals, drugs, and so forth. The indirect costs are the costs of illness and death. These costs are incurred when illness results in absence from employment, prevents homemakers from performing their duties or results in permanent disability that prevents employment.

It is important to put a dollar value on the services of the homemaker; otherwise her services are valued as zero. In any comparison with other diseases that affect the working population, which is still predominantly male, the homemaker is left out. Without going into detail, the calculation of the morbidity costs involves applying average earnings by age and sex to work years lost; attaching a dollar value to homemaker services, and applying it to homemaker bed days; and applying labor force participation rates and earnings by age and sex to persons in and out of institutions who are too sick to be employed or to keep house, under the assumption that if they did not suffer from these diseases, they would be employed at the labor force participation rates for their category.

The mortality costs shown in the table are the present values of future earnings lost for people who die prematurely, discounted at a rate of 10 percent. In fiscal 1975, the total economic costs of all diseases was \$220 billion, 45 percent of this being the direct costs with a remainder almost evenly divided between the costs of morbidity (26 percent) and mortality (29 percent). For arthritis and rheumatism, 61 percent of the total costs were indirect and almost all of this results from morbidity. Arthritis causes comparatively few deaths--only 2,454 deaths out of 1.9 million in 1976, and less than 1 percent of the total economic cost of these conditions was due to mortality. But the important point is that for these conditions, the morbidity costs are very high,

TABLE 12. Estimated Economic Costs and Percent Distributions According to Disease Category and Type of Cost, Fiscal Year, 1975

Disease Category	Total	Type of Cost			
		Direct Cost*	Indirect Cost		
			Total	Morbidity	Mortality**

Amount in Millions					
All diseases	\$219,749	\$ 99,373	\$120,375	\$ 57,848	\$ 62,527
Chronic diseases	133,135	56,479	76,656	37,101	39,555
Arthritis, rheumatism	6,547	2,541	4,006	3,951	55
Other chronic diseases	126,588	53,938	72,650	33,150	39,500
Acute diseases	86,613	42,894	43,719	20,747	22,972

Percent of Total					
All diseases	100.0	45.2	54.8	26.3	28.5
Chronic diseases	100.0	42.4	57.6	27.9	29.7
Arthritis, rheumatism	100.0	38.8	61.2	60.3	0.8
Other chronic diseases	100.0	42.6	57.4	26.2	31.2
Acute diseases	100.0	49.5	50.5	24.0	26.5

Percent of all Diseases					
All diseases	100.0	100.0	100.0	100.0	100.0
Chronic diseases	60.6	56.8	63.7	64.1	63.3
Arthritis, rheumatism	3.0	2.6	3.3	6.8	0.1
Other chronic diseases	57.6	54.3	60.4	57.3	63.2
Acute diseases	39.4	43.2	36.3	35.9	36.7

*Excludes unallocated expenditures for prepayment and administration, government public health activities, other health services, research and construction.

**Future mortality costs are discounted at a rate of 10 percent, adjusted for a rise in productivity of approximately 2 percent.

SOURCE: Lynn Paringer and Aviva Berk, "Costs of Illness and Disease, Fiscal Year 1975," Public Services Laboratory, Georgetown University, Washington, D.C., January 4, 1977. Costs of arthritis and rheumatism were estimated by the National Center for Health Statistics.

so that although arthritis and rheumatism contributed only 3 percent of all the costs, this amounted to \$6.5 billion in fiscal year 1975. If you apply a 12 to 15 percent annual rate of increase, that cost is certainly high today.

Arthritis is a special concern of this forum and exemplifies the health problem faced by many victims of chronic disease. At its worst, arthritis can cause great pain, deformity of limbs, blindness, and early death. Years of pain and frustration are the lot of those severely afflicted with this chronic disease.

Although it is impossible to measure the full toll of arthritis and other chronic diseases, the National Center for Health Statistics provides several important measures of the impact of illness. Data from the Health Examination Survey, the Hospital Discharge Survey, the National Nursing Home Survey and the Health Interview Survey indicate the burden of disease in terms of use of hospital care, nursing home care, physician services, and in terms of the prevalence of the disease.

The various indices of the burden of illness measure the impact of illness on the use of resources, days lost from major activity (including children's schooling), and years of life lost. By attaching dollar values to these indices, the economic cost of illness is measured in terms of the direct outlays for use of resources for hospital, physicians, and nursing homes, and the indirect costs or loss in output due to disability or premature death.

What is not measured by these dollar figures is the effect of arthritis and other chronic diseases on the quality of life. The closest we get to measuring the quality of life is with the data on limitation of activity, which just says that a person suffering from any disease is limited in activity; some of them are unable to carry on, and some can carry on only with limitations. That is inadequate, but quality is very difficult to quantify.

Arthritis represents a relatively small but significant part of the total burden of disease. It obviously affects women more than men and increases drastically with age. Those of you who are addressing the important questions of this forum about how to educate the professional have a very important duty ahead of you. I wish you success. Thank you.

For references, see the bibliographies at the end of the proceedings.

GENERALIST, ENTRY-LEVEL EDUCATION

BACKGROUND ON GENERALIST EDUCATION

Arthritis, as one of the major crippling chronic diseases affecting approximately 40 million children and adults, requires a large pool of health professionals prepared to function in academic and clinical roles in rheumatology. The National Arthritis Advisory Board has reported that a generalist in nursing or allied health may have as many as 365 encounters per year with rheumatology patients, so the extent and adequacy of entry-level preparation for dealing with these patients is of great importance.

To address the question of current rheumatology content in entry-level programs, the arthritis health professions section of the Arthritis Foundation conducted an undergraduate curriculum study recently under the direction of Alan Jette. This mail survey contacted directors of nursing, occupational and physical therapy undergraduate programs in the United States and Canada. The response rate was 73 percent of the 262 survey forms sent out.

Table 1 shows the number of courses taught in nursing, occupational and physical therapy preparation programs that directors recognized as including some rheumatology content. In the majority of nursing programs, one or two courses included rheumatology content. In physical therapy, there was a somewhat greater spread in terms of the percent of respondents reporting as many as three or four courses with such content. And in occupational therapy, there was an even greater spread, with several schools reporting five or more courses with rheumatology content.

Table 2 shows the total number of classroom hours that undergraduates were exposed to rheumatology content during the didactic portion of their basic professional preparation. The number of hours in nursing ranges from 4 to 25, with the greatest percentage of respondents (47) reporting zero to 4 hours, and 33 percent, 5 to 9 hours. Physical therapy reported a little more--24 percent having 5 to 9 hours, 24 percent 10 to 14 hours, and 32 percent, 15 to 25 hours. Occupational therapy was not too dissimilar with 24 percent reporting 5 to 9 hours and 35 percent, 15 to 25 hours. Even giving everyone the greatest benefit of the doubt, basic exposure to rheumatology content represents 1 to 2 percent of the total curriculum at the very most.

Since only 1 to 2 percent of didactic content is devoted to rheumatology, it is natural to ask what percentage of generalists' practice is spent on rheumatology. Marjorie Becker reported that a quick sampling of patient statistics at the University of Michigan Medical Center showed about 2 percent of the discharges were rheumatic disease patients--in line with the national figures reviewed by Mrs. Rice. However, about 7.5 percent of all the treatments provided in the physical therapy department were for some rheumatic disease problem, secondary complication, surgical rehabilitation, reconstruction, etc. The point is that, taking

TABLE 1. Total Number of Courses in Undergraduate Programs in the United States and Canada Which Include Some Rheumatology Content, by Discipline

Discipline	United States					Ave. No. Courses	Canada					Ave. No. Courses
	1	2	3	4	5+		1	2	3	4	5+	
Nursing (No. of respondents)	54% (28)	29% (15)	12% (6)	4% (2)	2% (1)	(1.7)	10% (1)	40% (4)	40% (4)	10% (1)	0	(2.5)
Physical Therapy (No. of respondents)	34% (100)	29% (17)	20% (12)	10% (6)	7% (4)	(2.3)	50% (3)	33% (2)	17% (1)	0	0	(1.7)
Occupational Therapy (No. of respondents)	12% (4)	35% (12)	24% (8)	15% (5)	15% (5)	(2.9)	17% (1)	50% (3)	33% (2)	0	0	(2.2)

TABLE 2. Approximate Number of *Total* Classroom Hours Spent on Rheumatic Diseases Over the Course of a Typical Student's Undergraduate Education, in the United States and Canada, by Discipline

Discipline	United States						Canada					
	0-4	5-9	10-14	15-25	26-50	50+	0-4	5-9	10-14	15-25	26-50	50+
Nursing (No. of respondents)	47% (27)	33% (19)	16% (9)	4% (2)	0	0	22% (2)	44% (4)	11% (1)	22% (2)	0	0
Physical Therapy (No. of respondents)	3% (2)	24% (14)	24% (14)	32% (19)	12% (7)	5% (3)	0	0	0	43% (3)	57% (4)	0
Occupational Therapy (No. of respondents)	8% (3)	24% (9)	19% (7)	35% (13)	11% (4)	3% (1)	0	0	14% (1)	43% (3)	43% (3)	0

SOURCE: A. M. Jette and M. C. Becker, "Allied Health Professional Preparation in Rheumatology," *Journal of Allied Health Education* (in press, November 1980); tables published by permission of Dr. Jette.

physical therapy as one example, the amount of time spent by generalist clinicians in a large teaching hospital (where many generalists are found), seems out of proportion to the amount of didactic preparation they have had.

To go back to the survey, table 3 gives curriculum directors' opinions as to the adequacy of present rheumatology offerings in their programs. When the comments on survey responses were interpreted, practically all of them came down to this: "We are already overloaded. We can't squeeze one more thing into that program." It is surprising, therefore, that from their point of view, current didactic content in rheumatology is perfectly adequate to turn out generalist clinicians. On the other hand, table 4 indicates that curriculum directors felt that the clinical portion of their programs probably included too little rheumatology experience.

This portion of the survey, as small as it was, suggests that curriculum directors in basic entry health professions programs do not feel that there is need for increased didactic exposure to rheumatology. That should be taken as fact. So any efforts to "invade" or expand those curriculums should focus on the clinical practicum where there is some recognition of need for increased exposure.

The Arthritis Plan said that health manpower in rheumatology should be expanded. Data for the past 10 years, however, show that there has been little or no increase in the total number of entry-level health professionals entering this field. The big bulge of program expansion is over; that suggests that efforts to improve preparation for arthritis care should be applied to existing programs. The survey reported above provides no evidence about the quality or appropriateness of the minimal amount of rheumatology content in basic programs, and this is something that should be of concern. Furthermore, in some cases, content relevant to care of arthritis patients is hard to separate from other program components. For example, gait training, the use of physical agents and modalities, and the use of evaluative techniques are being taught in all physical therapy curricula and all are relevant to arthritis care, but these methods are not usually thought of as specific preparation for work with arthritis patients, i.e. as "rheumatology." It is important to evaluate the quality and content of existing programs to see whether that content should be altered or supplemented in order to provide students with the necessary knowledge and experience to provide safe care and relevant referrals for arthritis patients.

TABLE 3. Evaluation of the Amount of Undergraduate Classroom Time Spent on Rheumatology in the United States and Canada, by Discipline

Discipline	United States			Canada		
	Too Little	Just Right	Too Much	Too Little	Just Right	Too Much
Nursing (No. of respondents)	24% (14)	75% (44)	1% (1)	13% (1)	87% (9)	0
Physical Therapy (No. of respondents)	31% (19)	69% (42)	0	0	100% (8)	0
Occupational Therapy (No. of respondents)	24% (9)	76% (28)	0	0	100% (7)	0

TABLE 4. Evaluation of the Amount of Undergraduate Clinical Exposure to Rheumatology in the United States and Canada, by Discipline

Discipline	United States			Canada		
	Too Little	Just Right	Too Much	Too Little	Just Right	Too Much
Nursing (No. of respondents)	33% (16)	65% (31)	2% (1)	33% (2)	67% (4)	0
Physical Therapy (No. of respondents)	39% (17)	59% (26)	2% (1)	25% (2)	75% (6)	0
Occupational Therapy (No. of respondents)	52% (14)	48% (13)	0	50% (3)	50% (3)	0

SOURCE: A. M. Jette and M. C. Becker, "Allied Health Professional Preparation in Rheumatology," *Journal of Allied Health Education* (in press, November 1980); tables published by permission of Dr. Jette.

NEEDS FOR FUTURE WORK IN ENTRY-LEVEL EDUCATIONAL PROGRAMS

Based on this background and further discussion of specific issues in generalist professional preparation, forum participants proposed the following recommendations for consideration by the National Arthritis Advisory Board.

Curriculum Content for Basic Professional Programs

Forum participants suggested that entry-level nursing and allied health programs should include the following areas:

- ° Pathophysiology and natural history of common rheumatic diseases
- ° Interrelationships of pain, drugs, environment, behavior, activity level
- ° Impact of rheumatic diseases on patients at various developmental levels
- ° Methods of measurement and evaluation used in clinical settings
- ° Components of comprehensive care for chronic diseases, including consideration of psychosocial aspects of disease
- ° Guidelines for referring patients and how to use community resources
- ° Specific disciplinary contributions to arthritis care, with emphasis on interdisciplinary cooperation
- ° The tools for a problem-solving approach to patient care
- ° Preparation for teaching--not just treating--patients with arthritis and other chronic diseases.

In considering what basic curriculum content in rheumatology should cover, it may be helpful to address such basic questions as these: What takes the rheumatology patient to the health professional? What should students know, do, be exposed to, in order to help care for the arthritis population? How can students be taught to apply specific evaluative and therapeutic techniques to a variety of patient problems?

The forum discussion of such issues resulted in identifying the needs for curriculum content outlined above. Selection of educational objectives and content should be based on a realistic analysis of the demands of clinical practice and of the health care system in which graduates will be expected to function.

In order to practice effectively, students must have a basic understanding of the pathophysiology and natural history (including the vari-

ability and unpredictability) of the common rheumatic diseases, and the most common physical and psychosocial problems related to them. Some pathophysiology and treatment approaches can be taught in the broader content of study of a general area such as the musculoskeletal system or approaches to chronic disease. However, there is some uniqueness to the inflammatory process in rheumatic disease and to its destructiveness that argues for specific rheumatology content in the curriculum. For example, students should be taught the differences between applying the evaluation and treatment techniques they have learned to someone with normal joints and to someone with inflamed and painful joints.

In order to address patients' problems, evaluate their status and judge the effectiveness of treatment, it is also important for generalist clinicians to understand the complexity of arthritis and other chronic diseases and the importance of such factors as the impact of disease onset at various developmental stages (juvenile, adult, and geriatric) and the interactions of pain, mobility, drugs, behavior and environment. Students should learn the components of comprehensive care from early detection to rehabilitation and from the impact of a pain medication to the impact of a patient's ability or inability to control such environmental factors as working conditions.

Comprehensive care should be based on an appreciation of the chronic nature of arthritis. Health care professionals are still, for the most part, crisis-oriented; they treat immediate symptoms. Until there is a cure for arthritis, this approach is inadequate for the patient with arthritis. For acute problems, a focus on treatment may be appropriate, but in chronic problems teaching is more appropriate--teaching people how to deal with their problem 365 days a year.

Students should also learn how to determine when they have reached the limit of their skills and referral is in order. This ability is closely tied to an understanding of the medical/surgical rehabilitation approach to patient care so that students know where their discipline and skills fit into the total picture. The importance of the team approach to arthritis management can be more fully appreciated when one realizes that the chronic nature of arthritis creates a complex management problem. Health professionals are not just treating a temporarily "sick" joint but must treat a person whose whole life has been/will be altered by a progressive disease for which there is no cure. Educational programs should emphasize the need for strategic use of a variety of therapeutic and psychosocial resources to assist arthritis patients.

Students in basic professional programs should be educated rather than trained. A person who is broadly educated--liberally educated--may avoid being too narrowly focused on a disease problem and may be better able to deal with the whole constellation of problems a patient may have. Rather than presenting a "how-to" approach to arthritis management, education should be geared toward providing a philosophy of treatment, a framework and the tools for problem-solving.

Basic Educational Methods and Resources

Forum participants recommended that instructional methodologies and resources should be expanded and strengthened by:

- ° Broader sharing of instructional methods and materials developed at Multipurpose Arthritis Centers and in other educational and clinical programs.
- ° Development of more programmed, self-paced teaching modules on arthritis to supplement faculty expertise in arthritis care. These should be designed so that they can be used by different disciplines and in varied educational settings.
- ° Expanding the sections on treatment in The Primer on Rheumatic Diseases to include services commonly provided by nurses and allied health professionals.
- ° Identifying minimum library holdings on arthritis that should be available in entry-level nursing and allied health programs.
- ° Expanding opportunities for students to learn methods of care for chronic disorders such as arthritis through supervised practice in clinical settings.
- ° Educating medical, allied health, and nursing students together in an environment where they see faculty and practicing professionals actually cooperating in teams.

As a result of recommendations in the Arthritis Plan, many Multipurpose Arthritis Center core faculty are developing teaching materials. One example is a teaching guide in rheumatology for physical therapy education from the University of Michigan. It is essentially a syllabus that has been overlaid on a physical therapy curriculum. Personnel from the Multipurpose Arthritis Center teach it in just 6 hours, and it can be substituted for the 6 hours of rheumatology content already in the curriculum. Staff of the Multipurpose Arthritis Center at Washington University in St. Louis has also prepared such "packages," and there are other examples of this kind of activity as a result of individuals being able to concentrate on arthritis care and education within the centers.

During the past year, the National Arthritis Advisory Board has begun, in an organized way, to ask the Multipurpose Arthritis Centers to share educational materials and methods that they are developing. The hope is that these might be made available through the Arthritis Information Clearinghouse. These centers are certainly not the only places where important and valuable curriculum developments are taking place. Many of these developments would be of general interest, and the Arthritis Information Clearinghouse is interested in collecting curriculum materials from others who have developed them, even in rough, unpolished form--for example, mimeographed curriculum guides and reading lists.

An extension of the Arthritis Plan ought to ensure that every basic professional entry program have a core curriculum or series of core curriculum modules on arthritis--both general and discipline-specific. These ought to be mandated because they would then form a consistent base of preparation in arthritis. One means of accomplishing this might be through a national task force, convened at regular intervals to review and update recommended audiovisual and written materials which could be made available to educational institutions through the Arthritis Information Clearinghouse. As many of these modules as possible should be in formats that allow the student to work/learn at his own pace (e.g., programmed learning) and which include practice in problem-solving. This would facilitate their inclusion in basic curricula and supplement faculty expertise in arthritis care. These should be designed so they can be used by different disciplines and in varied educational settings. One very specific step that should be taken is the expansion of sections on treatment in The Primer on Rheumatic Diseases to include services commonly provided by nurses and allied health professionals.

Another basic support for generalist programs would be to establish recommended minimum library holdings on arthritis to back up and augment rheumatology content in the curriculum.

College and university programs should make greater use of clinical facilities to teach students how to apply and adapt the general theory and methods they are learning to make them appropriate to dealing with chronic disorders such as arthritis. One example of such an effort is at St. Margaret's Hospital in Pittsburgh. Junior physical therapy students are brought into the hospital for 8 to 12 hours of lectures and clinical assignments over a 2-day period. This helps students integrate the skills they are taught in their discipline while applying them directly to rheumatology.

Experience in clinical settings should also be used consciously to bring together medical, allied health and nursing students where they can observe faculty and practicing professionals functioning together as a team to provide comprehensive care. Ideally, students will see that in addition to the specialized knowledge and skills each team member has, an attitude about working together makes the difference between a group of professionals practicing together and the same individuals functioning as a team. Interaction between members of the team, directed toward a common goal of comprehensive patient care with optimal patient outcome is the true intent of team practice.

An informal survey of Multipurpose Arthritis Centers showed that only 1 out of 20 respondents felt that their center did not have a team. However, individual centers reported a great variety of definitions of what constituted the team, what the team's functions were, and how the success of team practice was measured. Therefore, for the centers to provide valid data on the team concept--and certainly valid data are needed--more direction should be provided on what constitutes a team and what methodologies can be used to evaluate team practice.

There are some interdisciplinary models for preparing team members that can be examined. The simplest is a workbook called Improving the Coordination of Care--A Program for Health Team Development prepared with support from the Robert Wood Johnson Foundation which has special interest in delivery systems for chronic disease care. The program consists of seven 3-hour modules. The group is led through steps to improve coordination and planning for effective teamwork. Another example comes from a book on interdisciplinary child development teams and uses the competency based approach. A third, and more involved example, is a report from the University of Southern California occupational and physical therapy programs on a planned, interdisciplinary curriculum of both theory and practice in team building, including sessions on leadership styles, communication, group decision-making, and team effectiveness assessment.

Faculty Preparation to Teach Arthritis Content

To increase the number of faculty prepared to teach basic principles of arthritis care, forum participants felt that a need exists to:

- ° Provide short-term traineeships in rheumatology for faculty from basic professional programs in nursing and allied health.
- ° Make greater use of active clinicians as teachers.

Many faculty members in basic professional programs themselves lack adequate training in rheumatology. One mechanism that might be used to encourage undergraduate or basic professional faculty to take an interest in rheumatology is provision of short-term traineeships in rheumatology. Faculty need to be prepared both to teach students in the classroom and to serve as role models in the practice setting. Post-master's fellowships should be offered for faculty who might have an interest in this area; right now at the master's level in nursing, for example, six schools offer either a rehabilitation or chronic disabilities major. If something can be done to train master's level nurses and allied health professionals so that they can integrate this content into undergraduate programs, it would make a significant difference. Furthermore, academic faculty are more and more concerned that they are losing their clinical skills. So the focus of post-master's traineeships should be not only to strengthen teaching techniques and content but also to strengthen clinical skills. Faculty could then direct their undergraduate students not just in content but in the application of their knowledge to the real world, to the care of patients.

Another approach is to prepare practicing clinicians and to have them do more teaching. New graduates of entry-level programs often have a number of splinter skills. They have accumulated a great deal of information during their undergraduate years, and they want to hurry up and try it out. But when they apply their skills with a chronic patient such as a rheumatoid patient, they often fall flat on their faces and find it very discouraging that the patient isn't immediately getting

better. To better prepare students, educational programs should draw on the resources of the practicing field--those clinicians who roll up their sleeves and work with patients 8 or 10 hours a day. These people can come into the classroom and explain to students the difference between applying their knowledge to acute situations and molding and applying it to chronic situations. This approach has been tried recently at Howard University with a tremendous response.

Continuing Education for Generalist Clinicians

To assist graduate nurses and allied health professionals to keep up with changes in the care of patients with arthritis, forum participants identified a need for:

- ° Making more current information on arthritis care readily available to generalist practitioners
- ° Continuing education programs on arthritis care for generalist clinicians, some of which should be provided by Multipurpose Arthritis Centers.

Only 2 percent or so of the population of rheumatoid arthritis patients may need the resources and skills available in teaching hospitals or arthritis centers. The 98 percent remaining need the support of generalist practitioners and are more remote from major care centers. So the problem is, how do you relate what is going on at the centers to the real world of this large number of people in terms of improving function and coping with their environment in the home setting? One important step is to make information on arthritis care readily available to the primary care providers--family practice physicians and internists, along with nurse practitioners, physician assistants, and others.

The National Health Service Corps is part of the Bureau of Community Health Services, which includes Community Health Centers. It is hoped that over the next several years there will be 2,000 of these community centers throughout the country beginning to address the needs of 50 million underserved Americans. It will be important to communicate more of what the specialists are and what they do to facilitate cooperation with people in the primary care settings.

Another means of providing additional or continuing education for generalists is through short courses or traineeships, some of which could be offered at Multipurpose Arthritis Centers. Resource materials or self-study units should also be developed for use by primary care professionals at their home bases.

At the Johns Hopkins Multipurpose Arthritis Center, for example, the following types of programs are ongoing: A rheumatology update for physicians and allied health professionals is held every 2 years. During the alternate year, a 2-day nursing seminar for registered nurses and student nurses is offered. Updates offered four to five times

a year and designed for professionals and the public are held in outlying areas of Maryland. The Maryland Society for Rheumatic Disease holds five educational programs for physicians and allied health professionals each year. Arthritis health professionals have also organized a journal club for exchange of information. These types of educational activities are not unique to Maryland or to the Johns Hopkins center but are a reflection of educational programs across the country. Many of these programs are designed for the generalist, but it is the increasing numbers of arthritis specialists who have made them possible.

A short-term training program at the University of California, Los Angeles, recognizes that generalists see many arthritis patients but that arthritis care is not their only specialty area. They want to know about rheumatology, but not be confined to a full year's fellowship that concentrates on that area alone. A program has therefore been developed to train an interdisciplinary group over a 6-month period. The program is organized into three phases with varying periods of time spent at the training institution--1 week during the first month, 1 day during the third month, and 3 days during the sixth month. The instruction is arranged to allow trainees the opportunity to utilize their new knowledge in their own clinical setting and then return to the training institution to work out any problems they may be encountering and to allow emphasis on certain aspects of patient care in each of the three phases. The program also includes compilation of a "learning notebook" divided into major instructional modules for rheumatic diseases. Each module contains audiovisual and reading assignments and appropriate clinical experiences. Also planned are establishment of annual 1-day refresher courses and standardization of the program for application in a variety of clinical settings.

Finally, if health professionals are to be involved in rheumatology training programs and in continuing education programs, the rewards for their involvement should be more than intrinsic. Award of continuing education units for quality educational programs in rheumatology should be supported.

SPECIALIST PREPARATION

BACKGROUND ON SPECIALIST EDUCATION

Specialists prepared at the graduate level should gain increasing depth of knowledge in the specifics of arthritis pathology and various interventions. Programs should also include knowledge and skills for assuming leadership positions which may include a combination of responsibilities in service, education, and research. Opportunities should be provided for common learning in the sciences basic to this specialty area as well as experience in interdisciplinary care delivery.

Clearly, we have come a long way in development of arthritis specialists since the Arthritis Plan was written; however, there continue to be areas in which improvement is needed. The section of the Arthritis Plan which focuses on arthritis centers emphasizes the importance of arthritis health professionals within the Multipurpose Arthritis Centers. For example, one recommendation in the Arthritis Plan states:

Each Center should be developed and supported to undertake urgently required activities, education of patients, their families, the public, and health professionals, including education at all levels for a variety of providers of care.

And an even more powerful statement is:

Education and training of both patients and health professionals in the field of arthritis are critical for successful implementation of the entire Arthritis Plan. An immediate top priority placed on education and training is dictated by the nature and scope of the problem.

The Multipurpose Arthritis Centers have provided the base, in clinical terms, for increasing the opportunities for nurses and allied health professionals to become arthritis specialists. At the Johns Hopkins center, for example, nursing and allied health faculty have the same university commitments and expectations as do physicians--in health related research, in education, in patient services, and in community action. Within many of the centers there has been not only an increase in the numbers of nursing and allied health arthritis specialists, but also a marked expansion of their professional activities, in both quality and quantity. Many of these arthritis specialists are involved in providing continuing education programs for health care providers; and the development of education and information programs for patients, their families, and for the general public. Nursing and allied health arthritis specialists have also pursued some of the research topics identified in the Arthritis Plan, particularly those related to physical medicine.

Since the inception of the Arthritis Plan, educational opportunities for specialization in arthritis care and research have increased. This has been reflected in the growing attendance at the annual meeting of

the arthritis health professionals section of the Arthritis Foundation-- up to 315 registrants last year from 40 at the first meeting 15 years earlier.

An increasing percentage of nurses, occupational therapists, and physical therapists are pursuing graduate degrees, and graduate faculty are recognizing that rheumatic disease programs may have much to offer. At Johns Hopkins there are currently one or two graduate students in nursing per year affiliating with the rheumatology program. They are gaining knowledge (both didactic and clinical) regarding rheumatic diseases; some are completing their thesis requirements in that area, and several do their teaching practicums in rheumatology. There is something of a snowball effect: two of the master's prepared nurses who affiliated with the Hopkins program have joined nursing school faculties and introduced rheumatology into the basic curriculum. And it was only after designation as an arthritis center that a clinical physical therapist at that facility was offered a faculty appointment at the University of Maryland and has thus had the opportunity to increase the rheumatology curriculum for physical therapy students from 1 hour to 16.

A second major commitment of arthritis specialists is a commitment to research. Once again, the Multipurpose Arthritis Centers have been instrumental in stimulating nursing and allied health professional research activities and in providing the milieu and the support for those initiatives. Nursing and allied health professionals' applications for research support submitted to the Arthritis Foundation have been improving gradually over the years as concerted efforts are being made to upgrade their research skills--a process that must continue.

There is reason to be optimistic not only about the increasing number of arthritis specialists, but also about their ever-increasing contributions in education, in research, and in the improvement of care for patients with rheumatic disease. Momentum in these areas must be sustained or increased, and additional attention should be given to other recommendations in the Arthritis Plan related to the arthritis specialist which have been implemented only minimally or not at all.

NEEDS FOR FUTURE WORK IN PREPARING ARTHRITIS SPECIALISTS

Based on this background and further discussion of specific issues in specialist preparation, forum participants proposed the following recommendations for consideration by the National Arthritis Advisory Board.

Objectives of Arthritis Specialist Preparation

Forum participants suggested that more advanced professional education programs are needed to prepare graduate nurses and allied health professionals for such roles as:

- ° Clinical and faculty jobs which combine responsibilities in patient care, research, and teaching
- ° Consultant and leadership roles as clinical specialists
- ° Jobs in preventive programs such as occupational health nursing
- ° Positions in clinical and basic research.

Many of the objectives for educational programs to prepare nursing and allied health specialists in arthritis are quite broad and overlap with objectives for advanced educational programs in any field. Graduate level preparation should include attention to the three professional commitments of clinical teaching, research, and patient care. In comparing the career possibilities for nurses, occupational and physical therapists with those available to physicians whose interests are principally in rheumatology, the biggest and most disturbing difference is that it is expected that a physician who pursues an academic career in rheumatology will continue to see patients at the same time that he teaches and does research. For graduates in nursing and allied health, however, this is much more difficult to accomplish--difficult because the graduate programs which are the best established route to advanced credentials have tended to take people toward academic careers which did not include much patient care. It can be difficult to combine academic and clinical roles, but it can be done. For example, at Rush-Presbyterian-St. Luke's Medical Center in Chicago, all members of the faculty in nursing and in other fields are practitioner-teachers regardless of their level or discipline. Rush is unusual in its organizational structure, but at other institutions across the country, there are more and more opportunities for and recognition of blending or integrating all components of professional practice.

Two slightly more specialized roles may be added to the three described above: those of consultant and administrator. Preparing graduates to function in these roles may help them to integrate and maintain contact with patient care, education and research. The specialist needs to be able to consult with other nurses, other allied health professionals to help them integrate, within their plan of care, the specialist's knowledge about arthritis or other disease entities. In the role of

administrator, the specialist can function as a leader and change agent, helping to bring about changes, both in the educational system and in the practice setting to further improve the health care delivery system. These roles can be integrated very effectively in educating specialists--whether in arthritis or some broader area such as rehabilitation.

Not everyone is going to function in all of these roles equally. Emphasis for an individual may even change from time to time, but graduate specialists should maintain an awareness of all three roles, even though they may focus on one. For example, for those in community hospitals who don't have time for 100 percent integration, it may be useful to look at how to exchange, say 10 percent of a practitioner's patient care time for involvement in teaching, or to look for other ways to provide opportunities for at least some practice in other areas.

Students who will function in a variety of settings and with varying degrees of independence should also be well prepared for positions in health maintenance and disease prevention. Such specialists as occupational health nurses should learn how to identify arthritic and other chronic problems in order to provide early referral for treatment with the goal of preventing such problems from being aggravated and becoming more serious.

Finally, the necessity for training nurses and allied health professionals for formal roles in research becomes obvious if it is recognized that it is unusual for someone to be able to secure major research funding unless he/she (a) has an earned doctorate and (b) has served some sort of apprenticeship to establish a track record as a competent investigator. There are people without any degree who have good research ideas and sometimes excellent research competence, but in general, nurses and allied health professionals should meet established criteria in competing for research grants. For them to do this requires development of more programs at the doctoral level for nurses and allied health professionals to learn to become clinical researchers.

Resources and Programs for Specialist Preparation

Forum participants recommended that resources and programs for training specialists should be strengthened in the following ways:

- ° Multipurpose Arthritis Centers should support postgraduate and post-doctoral research training in nursing and allied health to prepare more of these professionals as clinical researchers in the field of arthritis.
- ° Formal programs of advanced practical experience (i.e., clerkships and residencies) should be developed in clinical facilities specializing in arthritis care.
- ° Traineeship/fellowship support for advanced preparation of clinical specialists and investigators from Federal agencies such as the

Bureau of Health Manpower and the Rehabilitation Services Administration should be increased.

Certification programs in arthritis as a subspecialty in nursing and allied health should be explored.

The Arthritis Act and, in particular, the Multipurpose Arthritis Centers, have made possible the evolution and expansion of the roles of arthritis specialists. In a field such as rheumatology which requires involvement by professionals of multiple disciplines and interests, the centers have been and are critical to development of new roles and opportunities. If the Arthritis Act is not renewed--if arthritis centers are not continued--the loss of arthritis health professional programs across the board would be calamitous.

Not all Multipurpose Arthritis Centers need to do the same thing; rather, each should determine its own specialty area and then develop training programs according to specialty area with a clearinghouse of information on the variety of center training programs available. Center directors should be permitted to use a certain portion of their funds to support postgraduate or postdoctoral research training in the fields of nursing and allied health to help develop a cadre of trained investigators interested in arthritis and other chronic disorders.

In the area of clinical specialization, it is still virtually impossible to find therapists with experience in treating patients with rheumatic disease. Late last fall, an article was published in one of the leading nursing journals describing the various roles and opportunities for nurses in the field of rheumatology. Within 2 weeks after the release of that journal article, 15 letters from registered nurses were received in the Arthritis Foundation's national office; these reflected not only tremendous interest in this area but also contained inquiries as to where an individual might go to gain knowledge and to develop expertise in the area of rheumatic disease. The foundation was hard put, as it has been in the past, to direct these individuals to programs where they could find a structured, intensive, educational program in rheumatology. Of the 114 accredited master of science in nursing programs in 1977, only 6 offered majors in rehabilitation nursing: University of Alabama in Birmingham, Rush University, Boston University, State University of New York at Buffalo, University of Wisconsin at Milwaukee, and California State University. Relevant knowledge, current practices and techniques of health care for patients with arthritis and related chronic conditions are essential components of rehabilitation nursing.

It therefore seems important, once the special capabilities of a center are determined, to move rapidly to establish rheumatology clerkships, internships, and concentrated educational experiences to meet the needs of nursing and allied health professionals seeking this kind of educational opportunity and ultimately to benefit the ever-increasing needs of the rheumatic disease population.

One major problem in developing such clinically based advanced training programs in nursing and allied health has been that Federal funds have not been available for training clinical specialists. The National Arthritis Advisory Board has recommended in the past that the staff of the Bureau of Health Manpower in both the Division of Nursing and the Division of Associated Health Professions review and revise existing guidelines for awarding traineeships and program support under the Nurse Training Amendments of 1979 and the Health Professions Education Assistance Act of 1976 to encourage use of these programs to support training of advanced nursing and allied health clinicians and clinical investigators.

The Bureau does not now fund disease-specific programs, so there are no funds specifically designated for arthritis or any other disease. The Division of Associated Health Professions has funded graduate training of allied health teachers and educators which could include some advanced study related to long-term care of patients with chronic disorders such as arthritis. However, funding for this training is now limited to completion of already approved projects, and prospects for additional support in the near future are not bright.

The Division of Nursing of the Health Resources Administration does have a number of programs that provide support for advanced professional training in nursing as well as money for nursing research. Theoretically, that money is available to people who want to put together programs in areas such as arthritis. However, applications to support the training of specialists in fairly narrow areas such as rheumatic diseases have very often not been well received by peer reviewers in that programs were considered to be too narrow. In at least three cases where programs with a narrowly defined clinical specialty have been supported, the programs have proven not to be viable after a couple of years, and they have had to be restructured with a broader scope. Programs to prepare clinical specialists to plan and provide long-term care using arthritis as an example or model do seem promising.

In developing clinical education programs, it was recommended that priority for training grants should be given to accredited graduate programs to offer an optional track in arthritis care within a rehabilitation major or to develop a specialty in management of arthritis and other chronic disabilities. Fellowship/traineeship programs could also fund students already in graduate programs. Faculties in institutions of higher learning with recognized expertise in the area of arthritis care could develop individualized programs of study for graduate students preparing for careers in teaching to enable them to learn a body of knowledge, clinical skills in arthritis care, and formal teaching skills to be used with students in basic educational programs. These fellowships could be provided either within or outside Multipurpose Arthritis Centers, but faculty mentors should have recognized skill and knowledge in the area of arthritis care.

Potential sources of funding other than Federal agencies should be investigated. Such sources include local Arthritis Foundation chapters.

For example, the Maryland Chapter of the Arthritis Foundation has established an arthritis health professionals fellowship to enable allied health professionals in Maryland to pursue a special line of study and/or clinical investigation related to rheumatic diseases and their management. The present grant of \$5,000 per year is expected to increase to \$19,000 per year in 1984-1985.

In part, failure to provide adequate specialist training reflects the fact that care of arthritis patients is not recognized as a bona fide subspecialty for nurses and allied health professionals, particularly in licensure or certification terms. In medicine, physicians may become board certified in rheumatology and thereby recognized as specialists. The same is not true for arthritis health professionals. Nurses, for example, may be certified as specialists in the areas of cardiology, oncology, rehabilitation, midwifery, and so on, but not in the area of rheumatology. If health professionals are to be involved in arthritis related graduate programs or in continuing education programs, the rewards for their involvement must be more than intrinsic. Obtaining credits for such educational programs and certification as arthritis care specialists would not only provide the extrinsic reward which many health professionals now seek, it could also serve as a stimulus for many health professionals to pursue rheumatology as a major career involvement.

On the other hand, such formal credentialing of specialists could not be done until the special expertise this should involve has been much more clearly identified. There is also a risk that this would increase the cost of services and fragment care for patients. Additional questions arise over the availability of positions for nurses and therapists with such a narrowly defined area of professional interest. Credentialing clearly remains a controversial topic.

In general, however, it seems likely that strengthening nursing and allied health education programs with regard to specialization in rheumatology will ultimately result in new and extended roles for these professionals in clinical service.

Public and Patient Education

Although public/patient education was not a formal topic for the forum, it was addressed in the Arthritis Plan, and a number of forum participants touched on it and suggested that:

- ° Priority should be given to health promotion through public education on arthritis; such programs should be supported by third-party purchasers of health care and by other representatives of the private business and industrial sectors.
- ° Patient/public education methods and materials should be carefully tested to determine their cost-effectiveness.

Forum participants spoke both of the inherent need for good patient education programs for health promotion and of the need to prepare nursing and allied health professionals to provide good education to individuals and to groups of patients. Priority should be given to health promotion, health protection and disease prevention rather than restorative care. Efforts should be made to have the public and government recognize that an "ounce" of chronic disease prevention can save dollars in years to come for an increasing population with chronic pathologies such as arthritis. This recognition is important if the traditional system is to open up a bit so that the services of health educators or patient advocates can be paid for.

The roles of the patient and the patient advocate depend upon people's philosophies, but patients come with a certain body of expertise, that is, what a disease and treatment are like for them. Furthermore, in order for treatment to be effective--especially for chronic conditions--the patient needs to understand and integrate information when it is appropriate. Professional evaluation of what the patient understands and applies is a very knotty problem that needs further exploration to determine effective methods of patient education and to enable judgments about patients' understanding of and compliance with treatment. This area would be particularly appropriate as a major emphasis in programs of advanced training for nursing and allied health arthritis specialists.

RESEARCH NEEDS IN ARTHRITIS

As a basis for forum discussion of research needs, three diverse "state-of-the-art" papers were presented. Despite the variety of their content, the discussion which followed and the written comments of forum participants resulted in a number of widely applicable research recommendations for consideration by the National Arthritis Advisory Board as well as a plethora of specific ideas for research projects.

GENERAL RESEARCH RECOMMENDATIONS

Forum participants made a number of overall recommendations for increased:

- ° studies in which arthritis serves as a model for a wider range of chronic disorders
- ° interdisciplinary research
- ° clinical studies of the efficacy of treatment methods now in wide use
- ° methodological studies to develop better ways of measuring key factors in arthritis care
- ° multicenter trials using comparable research methods and samples with pooling of data on clinical studies conducted throughout the country
- ° research on health promotion and methods of disease prevention.

To implement these recommendations, forum participants made the following more specific suggestions:

- ° A survey of nurses and therapists engaged in the treatment of arthritics should be conducted to determine what kinds of modalities are used, the frequency with which they are used, and the rationale for their use as well as to establish the total volume of services provided
- ° Studies that will help redefine the respective roles of professionals and patients to take into account the special needs of patients with chronic, disabling conditions
- ° Assessment of the long-range effectiveness and costs of providing followup to clients with chronic diseases such as arthritis
- ° Expansion of research on psychosocial aspects of arthritis and the significance of these factors in treatment

° A national conference should be held to bring together clinicians/researchers in arthritis to:

- Develop a model to describe the interaction of human function, symptoms, treatment and interventions with the course of arthritis as a basis for common agreement on education and research in the field
- Develop common terminology, identify promising research methodologies, and define patient populations for arthritis care research
- Pool clinical experience and research on the effectiveness of various treatment modalities
- Define research questions and share ideas on useful research instruments
- Assist in the development of a cadre of individuals interested in practice, teaching and research in arthritis
- Emphasize the importance and scope of nursing and allied health research related to arthritis

° Establish a national arthritis research information bank for storage, retrieval, and comparison of quantitative data on evaluation, treatment, outcome and long-term followup of patients to facilitate evaluation of effectiveness of care, tools for evaluation, and protocols for research.

In making these recommendations, participants recognized that many of these topics are of concern in other areas of chronic disease and long-term care. Investigators with a special interest in arthritis can thus contribute to and learn from work being done in other fields. In keeping with this, many of the research initiatives that were called for in the most recent National Arthritis Advisory Board report dealt with underlying mechanisms and problems that have broad application for many diseases besides arthritis.

The impact of arthritis on the individual's psychological and social world has been greatly oversimplified by researchers, probably because its manifestations are overwhelming: pain, uncertainty about the course, prognosis and treatment of the disease, possible chronic disability, poverty, unemployment, lack of physical and financial access to care, vulnerability to quackery, professional and social attitudes about chronic disability, deformity and the myth of the "arthritis personality," inability to perform simple daily tasks. The complex psychosocial ramifications of arthritis thus defy explanation by a single theory or perspective.

The Arthritis Plan calls attention to the fact that both health services and research in the United States have tended to focus on acute

conditions. Arthritis, with its impact on the quality of life of persons and their ability to function in the daily activities of work, self-maintenance, and leisure, can serve as a prototype for understanding chronic disease and disability in a society which desperately needs that knowledge to face the challenge of an increasing population of persons with chronic conditions. It may be self-defeating to insist that arthritis be singled out whether in a contract proposal, a research paper, or a literature search because these are pervasive problems. Where useful research on coping with chronic disease has not been done, however, arthritis may serve as a useful--but not exclusive--model.

Because of the complexity of arthritis and other chronic diseases, an interdisciplinary research approach is likely to be most effective and to avoid duplication of effort, as for example both nurses and physical therapists conducting separate projects on energy conservation.

The role of nurses and allied health professionals in the treatment and study of the rheumatic diseases is becoming broader and better understood by the patient population and the medical community. To maintain this impetus, it is important for these professionals to continue to develop a sound theoretical basis for their treatments and an increased sophistication in treatment skills. This incorporates not only the development of newer techniques, but also the evaluation of the efficacy of treatments presently being used. A cooperative, interdisciplinary, multicenter effort to identify and evaluate commonly used treatment techniques could provide useful and generally accepted results. Determination of the efficacy of treatment for relieving the patient and the cost-effectiveness of alternative approaches are both important.

In conducting such clinical research, it is essential that the interdisciplinary research team include the physician(s) involved in caring for patients who serve as subjects. Without this collaboration, important variations in other aspects of the patient's overall therapy may be difficult to control and their interaction with nursing and allied health interventions impossible to interpret.

The traditional physical modalities of heat, cold and massage have been applied to arthritis patients in the belief that they are somehow supposed to reduce joint swelling, promote circulation, stretch connective tissue, reduce pain and stiffness, and promote mobility. What is terribly distressing is that there is no sound basis for belief in the efficacy of these techniques. The major texts on arthritis written since 1975 include very little on underlying mechanisms felt to support use of these techniques, and 80 to 90 percent of the references predate 1960. One has to conclude that research on traditional physical agents and their effects on arthritic pain and mobility have been extremely neglected.

Similarly, new modalities such as joint mobilization, biofeedback, the relaxation response, and transcutaneous electrical nerve stimulation (TENS), are often adopted enthusiastically without adequate testing of

their efficacy. For example, transcutaneous electrical nerve stimulation is the placement of electrodes on the skin surface and passage of current through those electrodes to the point at which the patient feels a paresthesia or, under some circumstances, a muscle contraction beneath the stimulating electrodes. The premise is that for a painful region, this kind of input might serve as a counter-irritant or an inhibitor of pain perception. The mechanism for that inhibition is unclear. There have been only two studies that have dealt with the use of TENS with the arthritic patient; both are very encouraging, and both are very recent. However, these studies do not address questions of appropriate duration of treatment, number of treatments, or long-term effectiveness.

Everyone agrees that tests and treatments that cost the patient money should not be undertaken unless they are needed. However, without testing the benefit of various modalities, there is no way to determine whether or not they are needed. Alternatives also need to be compared, since pain may cause patients to use expensive quackery and potentially addicting drugs when some other treatment may be more effective and have fewer side effects.

Many tools are available for assessment of arthritis patients before and after treatment as a means of evaluating treatment efficacy. In many cases, the expensive equipment and elaborate studies conducted at major research centers can be translated into validated baseline data or simple assessment techniques or tools for application in a wide range of clinical settings.

Several of the major gait laboratories around the country have developed both simple and sophisticated instruments for analyzing gait patterns--a major concern for those treating patients with arthritis of the lower extremities. Foot switches are pressure-sensitive shims attached to the bottom of the foot so that as the patient walks, the pressure of body weight causes the foot switches to go on and off. The Rancho Gait Analyzer is based on foot switches and uses a micro-processor to record these characteristics of gait automatically: velocity, cadence, stride length, gait cycle duration, single and double limb support. This device can be used in any clinic. Mary Pat Murray, at the Wood Veterans Administration Hospital in Milwaukee, has used interrupted light photography in which the patient's limb is marked with light sensitive spots, and sequential photography is used to measure the angles of the joint and the time of heel strike, toe-off and so forth in the gait cycle. This is a somewhat laborious but reasonable alternative to more elaborate and expensive technologies.

The difficulty in using such devices to measure patient performance is that performance goals vary with individual patients, so one needs to use this technology not only for evaluation of individual patients, but also in the broader scope to study groups of patients and clusters of disabilities with the hope that one can improve care for classes of patients. It is also important to be aware of not just the acute disability and its immediate rehabilitation, but what happens to the

patient over a period of many years. Furthermore, the technology for measuring a problem and establishing criteria by which to judge it must be coupled with the knowledge and sensitivity that result in interpretation of the data collected in a manner that has practical meaning for the patient and for the objective for which the study is undertaken.

For example, research to examine one of the major problems in arthritis--the flexed knee deformity--found that walking with a 15 degree knee flexion contracture required 10 percent more energy than normal; at 30 degrees, 25 percent; and at 45 degrees of knee extension restriction, almost 50 percent more energy is required. This is the kind of index that physical therapists should look at in trying to assess the metabolic demands of disability on their patients' performances.

The kinds of research questions to ask regarding performance and to translate into clinical practice are these: What level of functional activity can be expected in a given patient under given conditions? When will he be able to perform in the manner expected, for how long, and at what intensity? What is the influence of the disease in the contralateral limb or what is the influence of the disease in the ipsilateral joints other than the diseased joints? What specific restorative procedures are indicated? How effective is the treatment program? What are the effects? Can they be quantified? How are realistic goals established and to what degree are they met?

To the extent that these questions can be answered in quantitative terms, it should be possible to enhance the efficiency and the quality of care at a reduced cost.

In the psychosocial area, there is a paucity of research regarding how persons with arthritis perceive their symptoms, about the relative importance of the symptoms of arthritis to the individual and about how psychosocial factors influence the manifestations of arthritis and patients' responses to treatment.

Earlier studies have suggested that the patient's uncertainty about the course of the disease, perception of pain, and preoccupation with illness all influence responses to treatment and rehabilitation, and the adoption of adaptive or maladaptive coping strategies. Further research on these topics could provide valuable insight into treatment methods, responses to intervention, and to the establishment of priorities and training methods to be used in rehabilitation.

Since arthritis is a chronic disease often resulting in lifelong disability, it presents a challenge to which one may either succumb or with which one may cope with varying degrees of success. Being able to describe the adaptive coping strategies of a sample of arthritics could enable rehabilitation programs to employ techniques to train persons in the use of such strategies.

The person with arthritis must deal with the competition between two imperatives, the physiological imperative of the body and the activity or "doing" imperative of the world. In attempting to balance these opposing forces, the individual adopts a variety of social and psychological tolerating strategies, and these include juggling the hope of relief or remission against the dread of progression, covering up and keeping up, acting normally, while pacing, renormalizing, or adjusting to reduced activity. Earlier studies of coping could well be refined and expanded to include the question of how effective these coping strategies are in preventing, avoiding, or controlling the emotional distress associated with arthritis and how coping strategies change with disease progression.

Studies are designed and implemented from the health professionals' point of view. Self-report of needs by patients could reduce the so-called specialist effect in which professionals perceive a patient's needs according to the services available. Such a needs assessment might provide a more comprehensive base for the development of intervention strategies and public policies for arthritis.

Further research should also be conducted to explore the relationship between ability to maintain independence in daily living activities and life satisfaction. Preliminary analysis indicates that there may be a positive and fairly strong relationship between successful performance of daily living skills and life satisfaction. Such relationships might lead to the development of a new definition of health which is based upon successful function to the patient's satisfaction in the community rather than health as an absence of pathology. You might call that functional health.

Greater emphasis should be given to health promotion, including early detection of problems and community-based provision of health care to increase accessibility. New models for provision of services should be explored, including the provision of services in such environments as consumer-operated independent living centers and community colleges.

At the same time, as such new patterns of service are explored, data should be collected to provide an accurate description of what is now being done. Although the statistics presented in her keynote address by Dorothy Rice make it clear that the total volume of care provided by nursing and allied health professionals is large, we still have little or no information on the frequency with which arthritis patients receive such services, how long they are seen, where treatment is given, what types of treatment and evaluation are used, and what results they achieve. Such data are particularly difficult to secure for nursing since those services are usually provided as a part of hospital care or in conjunction with a visit to a physician's office and are not reported separately for billing purposes.

One means of deciding what treatment/assessment methods are most commonly used in treating arthritis would be to distribute a questionnaire

to clinicians to determine the modalities used, the frequency of use, the rationale for use, and the assessment of their outcome. Where there is good evaluation to support use of modalities, that will be valuable in itself. Where there is not good information on effectiveness, that will point the way for needed clinical research.

To provide a focus for research in arthritis it would be useful to hold a national conference that brought together people who are working on instruments and measuring tools and some of the theoretical problems associated with arthritis. This could be a working session to develop strategies, to share information on what has already been done, on research instruments, and on clinical experience, to establish a uniform working vocabulary, and to define study populations. Such a conference might also develop a model to describe the interaction of human function, symptoms, treatment and interventions with the course of arthritis as a basis for common agreement on education and research in the field.

As research is carried forward, a national arthritis information bank should be established where quantitative data on evaluation, treatment, outcome and long-term followup can be stored and interpreted so that trends in effectiveness of care may be followed in a meaningful manner.

SUGGESTED RESEARCH FUNDING

A number of funding sources and strategies for nursing and allied health research related to arthritis were suggested during the course of forum discussions.

- ° A survey should be conducted to seek out information on various sources of research funding available for nursing and allied health investigators, especially in the behavioral and social sciences in which arthritis might be used as one example of the psychosocial and other aspects of chronic disease.
- ° Increased funds should be made available for funding research fellowships and doctoral research in arthritis by nursing and allied health professionals.
- ° The National Institutes of Health should make available joint clinical-research appointments for nurses and allied health professionals at the National Institutes of Health Clinical Center.
- ° Multipurpose Arthritis Center directors should be encouraged to allocate discretionary funds to projects and fellowships for clinical research in arthritis by nursing and allied health professionals.

Information should be collected--perhaps by the Arthritis Clearinghouse--on various sources of Federal monies available for research that are not tied specifically to nursing or to the allied health professions or to arthritis. These could be research funds for behavioral science

in which the design can be broad but use arthritis as an example. Resources might include behavioral science research grants, biomedical research grants, health systems research, etc.

The National Center for Health Services Research does not fund research on specific disease entities. If, however, arthritis research is focused on long-term care issues or on problems arthritis shares with other chronic diseases, projects may be fundable. For example, psychosocial problems and functional measures may fall within the center's purview. How do you deal with the chronic condition? How do you deliver care to people who can exist at home with some support services? Investigators should consider questions that need to be asked about arthritis which will be generalizable to other disease entities in order to make it more likely that funds from a variety of sources will be available.

Collaborative projects--interdisciplinary in design and interagency in funding--should be explored. More research and educational opportunities should be made available through a variety of channels for nurses and allied health professionals. For example, the National Institutes of Health, and its nursing department, exist to support biomedical research activities rather than clinical education. In the Arthritis Institute, nurses who enter that group need to begin by learning exactly what is transpiring with the clinical population and with the research protocols they help to implement. A possible future role for NIH could be along the line of a joint clinical-research appointment for nurses in which they could spend a year in clinical activities working with patients who are involved in a particular medical research protocol, then in conjunction with learning additional research methods, work specifically in nursing research for another year or two.

Multipurpose Arthritis Center directors should be encouraged to allocate discretionary funds to research training, projects and fellowships for clinical research in arthritis by nursing and allied health professionals. Some specific examples of arthritis health professional research at the Johns Hopkins University Multipurpose Arthritis Center cover the following areas:

1. Quantitation of muscle function in rheumatic disease.
2. Screening populations for rheumatic disease and the urgency of patients' needs for evaluation.
3. Physical therapy referral: Who, when and why?
4. Nursing assessment of patient perceptions/expectations.
5. Psychological factors in patients with rheumatic disease: a multidisciplinary study.

Such work should be continued and extended by broadening the scope of arthritis health professional research to include the total range of the rheumatic diseases and their management. (Currently, the Arthritis

Plan identifies only a few specific disease-related research areas for nursing and allied health professionals.) The continuation of Multipurpose Arthritis Centers should be supported in the strongest possible terms, since they represent an immensely valuable resource for the training of clinical investigators and for research to determine the effectiveness of present methods of nursing and allied health arthritis care.

RESEARCH SETTINGS

In forum discussions and written comments, participants suggested that the National Arthritis Advisory Board consider recommending that:

- ° Funding be provided for practicing clinicians as well as researchers to evaluate specific treatment modalities, evaluation techniques, cost/benefit of these to patients, and
- ° Multipurpose Arthritis Centers should evaluate critically any innovative practices they employ; such new techniques should then be evaluated in as wide as possible a variety of settings to increase the validity of findings on their value.

There was no disagreement on the importance of thoroughly and carefully researching the efficacy of assessment techniques and treatment modalities used with arthritis patients. It is clear that studies with sophisticated instrumentation are needed to answer the hows and whys behind specific mechanisms as well as to validate quantitative assessments used clinically to show that there is a difference in the outcome of patient performance as a result of therapy. Multipurpose Arthritis Centers and other institutions specializing in arthritis care can conduct important studies but should also provide formats that can be taken into the clinic and used in the community to obtain additional data and to develop clinically feasible methods of measurement. Many of the advances in clinical treatment are going to come from the practicing therapist who is able to evaluate subtle changes in patient response because he/she sees the day-to-day variation in patients' reactions to treatment. There should therefore be more research support and guidance for practicing therapists.

The links between research centers and clinical settings are essential to the translation of research results to the benefit of arthritis patients. Funds should be allocated to Multipurpose Arthritis Centers for the establishment of quantitative patient assessment programs which will serve several purposes:

1. Provide more definitive description of patient characteristics and improved assessment of outcomes of care;
2. Increase clinical research capability in the study of movement disorders; and
3. Improve the capacity of patient care personnel to evaluate the validity of their services.

Multipurpose Arthritis Centers should be encouraged to evaluate critically any innovative practices they use. The centers should cooperate in multicenter and community studies as well, since the greater the variety of settings and the variations on a common theme, the more worthwhile will be the findings because they can then be duplicated in a variety of settings.

TOPICS FOR STUDIES SUGGESTED BY FORUM PARTICIPANTS

In their written submissions and comments during the forum discussions, participants suggested many topics on which research is particularly needed. Topics and questions suggested by one or more participants included the following:

1. Patients' perceptions of their symptoms and needs, how they meet these needs using the resources available to them and how satisfied patients are with the services they receive.
2. Whether too much patient education adversely alters the patient's expectations of future treatment and if so, what this means in terms of the course of the disease.
3. What effect the multidisciplinary approach to patient care has on status, disease activity, social adjustment, and general satisfaction with care. Does the "team" make a difference?
4. The efficacy of frequently used modalities for prevention of joint damage and deformity, e.g.,
 - splinting
 - exercise for prevention of deformity
 - use of joint protection and energy conservation techniques
 - use of adaptive equipment.
5. Whether the techniques of joint protection and energy conservation now being taught to patients are logical when they are subjected to thorough biomechanical evaluation.
6. The effectiveness of physical agents, splinting, and other modalities in managing pain and which modalities are most effective with which type of problem. This should be research which does not judge pain as real or imaginary but which focuses instead on changes in functional performance.
7. The prevalence and economic impact of arthritis in specific communities.
8. The degree to which SHPDA's, HSA's and PSRO's include arthritis and other disabling chronic disorders in their plans.

9. Whether early detection, referral, treatment, and followup of employees and their families through an occupational health program prevents and/or retards the progress of arthritis to such a degree that insurance providers would be willing to offer a reduced premium to employers who provide such a program for their employees.
10. The efficacy of modifications in work patterns and equipment based on human factors engineering in preventing degenerative joint disease from repetitious trauma.
11. How the effects and efficacy of therapeutic exercise programs for arthritic patients vary with:
 - differences in the age of the patient
 - differences in joint loading (i.e., weightbearing vs. nonweightbearing)
 - use of high velocity, low torque loading exercise
 - adaptation of activity patterns.
12. What clinical tools are available for assessment of pain relief and how valid, reliable, and practical are they when used in the average clinical situation?
13. What role does motor behavior play in the individual response to pain?
14. What role does the central nervous system exert on the response of the joint-muscle complex to injury?
15. What is the effect on joints of faulty biomechanical alignment resulting from changes in muscle strength and from reduced physical activity?
16. What is the nature of progressive changes in muscular strength resulting from the primary muscle involvement, compensatory changes in posture, and reduced activity associated with arthritis?
17. What are the short- and long-range effects of drugs commonly used in treatment of arthritis on joint stiffness and muscle strength?
18. How should treatment priorities, methods of patient instruction, and treatment setting be varied to respond to differing needs and resources of particular socioeconomic and ethnic groups?
19. What is the relationship between physical impairment and handicap in occupational, domestic, recreational, and social activities and do interventions such as joint replacement produce the same degree of improvement in handicap as they do in physical impairment?

20. What factors are associated with patient/family compliance with recommended regimens for control of chronic disorders such as arthritis?
21. The cost effectiveness of different care delivery methods/ settings including evaluation of strategies for facilitating self-care, home-care, and team care.
22. What coping strategies arthritis patients use, how effective they are in preventing, avoiding, or controlling the emotional distress associated with arthritis, and how these strategies change as the disease progresses.
23. What are the principal environmental barriers to patient independence in hospitals, health care agencies, and homes?
24. What are the most common folklore and quack practices related to arthritis and which strategies are most effective with different age groups in changing their questionable health beliefs and practices?
25. What are the effects of chronic illness (e.g., pain and deformity) on the meaning and purpose of life, for example, the effect of isolation due to arthritic deformities and barriers to travel and transportation? Predictive rather than retrospective studies are critical.
26. What is the impact of outreach and continuing education programs on the nature and quality of services provided by nurses, occupational and physical therapists?
27. How do providers of services deal with their own feelings and attitudes toward arthritics/arthritis and other chronic diseases?
28. How can the specialized, often costly, measurement techniques used in the research laboratory be translated into low cost, simple measures for use in day-to-day patient care?
29. The relationship between the ability to maintain independence in daily living activities and life satisfaction.
30. How persons with arthritis experience their own symptoms, for example, what is the relative importance of such symptoms and consequences of their illness as deformity, pain, boredom, restricted mobility, sensory and social isolation, and the need to make changes in lifestyle?
31. How the patient's and family's expectations influence their compliance with recommended regimens.
32. How psychosocial factors influence the manifestation of arthritis and patients' responses to treatment.

APPENDIX A

BIBLIOGRAPHIES

Presenters and other forum participants provided references and bibliographies with their papers and written comments on forum topics. Although the papers could not be reproduced, it was felt that these bibliographies were of potential use, and they are therefore included with this summary of the forum proceedings.

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APPENDIX B

**FEDERALLY LEGISLATED SUPPORT FOR ADVANCED TRAINING OF
NURSES AND ALLIED HEALTH PROFESSIONALS**

Federally Legislated Support for Advanced Training of
Nurses and Allied Health Professionals

INTRODUCTION

This report describes a total of 51 sources of Federal funding. Thirty one programs providing student support for advanced training are identified; four of these programs are uniquely for nurses and three are uniquely for allied health professionals. The remaining 20 programs provide monies for educational program support. Excluding the Arthritis, Bone and Skin Diseases Research Training Program (National Research Service Awards listed in Table 1) and the Multipurpose Arthritis Centers' training efforts, no sources of Federal training monies for rheumatology as a specialty have been identified.

Information is provided on advanced training support for nurses, health educators, medical social workers, nutritionists and dietitians, occupational therapists, pharmacists, physical therapists, and vocational and rehabilitation counselors. For the purposes of this report, advanced training is defined as post-entry level training, meaning any education beyond that required for an individual to begin practicing a particular health profession. Professional groups vary widely in definitions of "entry levels," and requirements are in a state of flux. Generally, at least a baccalaureate degree is required. When a Federal program is listed for which registered nurses without the baccalaureate are eligible, this information is noted.

The data are presented in four tables, grouped by Federal agency. The first three tables list funding for which nurses and/or allied health professionals are eligible. Table 4 presents funding available to institutions of higher education and other organizations for purposes of developing and implementing advanced training seminars, institutes, or graduate and post-graduate educational programs.

Federal funding priorities in health care are being reexamined, and some of the programs listed might have expired by the time the report is printed. Opinions vary as to the need for funding for more entry-level nurses and allied health professionals in contrast to the need for support of advanced training of those already in the health field. The President's 1981 Budget recommends sharp cuts in funding for allied health and nursing projects, with remaining funds supporting advanced training to nurses. Upcoming appropriations decisions will reveal future trends for such funding.

NOTE: This appendix represents an abbreviated version of a report compiled by the Arthritis Information Clearinghouse. To receive the complete report, which contains further information about each Federal funding program presented in this appendix, contact the Clearinghouse at:

Arthritis Information Clearinghouse
P.O. Box 34427
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March 1980

TABLE 1. FEDERAL FUNDING FOR NURSES AND ALLIED HEALTH PROFESSIONALS

Name of Program (Legislative Authority) Objective	Agency	-Prerequisites -Type of Training -Award Conferred
FELLOWSHIPS		
<u>Graduate and Professional Opportunities (Higher Education Act of 1965, Part B only; expires 9/30/81)</u> Fellowships to support full time graduate and professional training of minority groups and women	DHEW/OE/Bureau of Higher and Continuing Education/Division of Training and Facilities	-Baccalaureate -Clinical, teaching, administration -Masters or doctorate
<u>Indian Education - Fellowships for Indian Students (PL 92-318; expires 9/30/83)</u> To support American Indians in study for careers in medicine, law, engineering, and related fields	DHEW/OE/Office of Indian Education	-American Indian support only; baccalaureate required -Clinical, administration, teaching, research -Masters, doctorate, post-doctorate
GRANTS		
<u>Vocational Education - Graduate Leadership Development Program PL 94-482; expires 9/30/82)</u> To support leadership, policy-making education for vocational educators	DHEW/OE/Bureau of Occupational and Adult Education/Division of Research and Demonstration/Personnel Development Branch	-Baccalaureate plus two years vocational education, related social research, or industrial or military training; or current or expected employment in vocational education -Administration, teaching -Non-degree, Masters, or doctorate
<u>Special Programs for the Aging - Training (PL 89-73; expires 9/30/82)</u> To attract and train persons for the field of aging	DHEW/Office of Human Development Services/Administration on Aging	-Must be on staff of state aging agency for in-service training; baccalaureate for graduate training -Clinical, research -Non-degree in-service training for state agency staff; Masters or doctorate for other trainees
<u>National Research Service Awards (NRSA) - Mental Health NRSA's for Research Training (PL 93-348, PL 95-622; expires 9/30/81)</u> To support research training in mental health	DHEW/PHS/ADAMHA/NIMH/Division of Manpower and Training Programs	-Baccalaureate -Research -Doctorate or postdoctorate in specified mental health related areas including aging and child mental health
<u>NIH National Research Service Awards (NRSA) (PL 78-410, PL 95-622; expires 9/30/81)</u>		
Note: There are 4 types of NRSA's and each of the NIH programs listed below may award any of the 4 types. 1. Institutional NRSA, Long-Term; 2. Individual NRSA; 3. Senior Fellows NRSA; 4. Institutional NRSA, Short-Term		

TABLE 1. FEDERAL FUNDING FOR NURSES AND ALLIED HEALTH PROFESSIONALS

Name of Program (Legislative Authority)	Agency	-Prerequisites -Type of Training -Award Conferred
GRANTS (continued)		
1. Institutional NRSA, Long-Term		-Baccalaureate -Research -Doctorate or postdoctorate
Objective: to support research training or broaden scientific background for persons training in biomedical or behavioral research		
<u>Aging Research</u>	DHEW/NIH/National Institute on Aging (NIA)	
<u>Arthritis, Bone, and Skin Diseases Research</u>	DHEW/NIH/National Institute of Arthritis, Metabolism, and Digestive Diseases (NIAMDD)	
<u>Diabetes, Endocrinology and Metabolism Research</u>	DHEW/NIH/NIAMDD	
<u>Digestive Diseases and Nutrition Research</u>	DHEW/NIH/NIAMDD	
<u>Immunology, Allergic and Immunologic Diseases Research</u>	DHEW/NIH/National Institute of Allergy and Infectious Diseases (NIAID)	
<u>Microbiology and Infectious Diseases Research</u>	DHEW/NIH/NIAID	
<u>Research for Mothers and Children</u>	DHEW/NIH/National Institute of Child Health and Human Development (NICHD)	
<u>Cellular and Molecular Basis of Disease</u>	DHEW/NIH/National Institute of General Medical Sciences (NIGMS)	
<u>Pharmacology-Toxicology Research</u>	DHEW/NIH/NIGMS	
2. Individual-NRSA		-Doctorate -Research -Postdoctorate
Objective: to support training to broaden research clinicians' scientific background or expand their potential for research		
<u>Same programs as listed under #1.</u>		

TABLE 1. FEDERAL FUNDING FOR NURSES AND ALLIED HEALTH PROFESSIONALS

Name of Program (Legislative Authority) Objective	Agency	-Prerequisites -Type of Training -Award Conferred
GRANTS (continued)		
3. Senior Fellows NSRA		-Doctorate plus at least 7 years experience -Research -Postdoctorate
Objective: to support training for experienced research scientists to change or broaden the direction of their research careers		
<u>Same programs as listed under #1.</u>		
4. Institutional NRSA, Short-Term		-Must have a baccalaureate or its equivalent or be in the fifth year of professional training; and must be enrolled in accredited school of medicine, osteopathy, dentistry, veterinary medicine, optometry, pharmacy, or podiatry -Research -Non-degree
Objective: to ameliorate future shortage of clinical investigators by supporting research training experience up to 3 months in length		
<u>Same programs as listed under #1.</u>		
<u>Minority Access to Research Careers - Faculty Fellowship Program (PL 78-410, PL 95-622; expires 9/30/81)</u> To support advanced research training for faculty from schools with substantial minority enrollment	DHEW/NIH/National Institute of General Medical Sciences	-Baccalaureate (the usual individual NIH/NRSA requirement of a doctorate is waived) -Research -Doctorate or postdoctorate
LOANS		
<u>National Direct Student Loans</u> (PL 89-329, PL 92-319, PL 94-482; expires 9/30/80, amendments pending) Establish funds at institutions for needy undergraduate and graduate students	DHEW/OE/BSFA/ Division of Policy and Program Development/Campus-Based Grant Branch	-Undergraduate or graduate student must prove financial need and ability to maintain good standing -Teaching, clinical -Masters or doctorate
<u>Guaranteed Student Loans</u> (20 USC 1071 and following; expires 9/30/81, amendments pending) To authorize low interest deferred loans for educational expenses	DHEW/OE/BSFA/ Division of Systems Design and Development/Guaranteed Student Loan Branch	-No education requirements from Office of Education; student must meet requirements of individual schools -Undergraduate, graduate, and vocational -Diploma, non-degree, baccalaureate, Masters, or doctorate
SCHOLARSHIPS		
<u>National Health Service Corps Scholarship Program (PL 94-484; expires 9/30/80)</u> To ensure supply of professionals for service in health manpower shortage areas	DHEW/PHS/HRA/ BHM/DMTS/National Health Service Corps Scholarship Program	-Baccalaureate in discipline acceptable for entry into graduate nursing and public health nutrition programs; scholarships offered in various disciplines, according to changing manpower shortage indications -Clinical -Masters in nursing or other targeted discipline

TABLE 1. FEDERAL FUNDING FOR NURSES AND ALLIED HEALTH PROFESSIONALS

Name of Program (Legislative Authority) Objective	Agency	-Prerequisites -Type of Training -Award Conferred
SCHOLARSHIPS (continued)		
Health Professions Scholarship Program for Indians (PL 94-437; continuing 3 year authorization, applying 2/80 for post FY 80 funding) Scholarship grants to American Indians and others for health profession education	DHEW/PHS/HSA/ Indian Health Service	-American Indian students receive priority selection; baccalaureate required -Clinical -Masters or doctorate in nursing; Masters or doctorate in dietetics or nutrition, pharmacy, physical therapy, public health, social work
TRAINEESHIPS		
Rehabilitation Services Administration Programs (PL 93-112, PL 94-230, PL 95-602; expires 9/30/82)	DHEW/OHDA/RSA/ Division of Manpower Development (Same as above for all five programs)	
1. <u>Long-Term Training Grants</u> To support basic or advanced professional training in rehabilitation		-1. Baccalaureate 3. Must be state vocational rehabilitation agency personnel 2.,4.,5. Information not available
2. <u>Experimental and Innovative Training Projects</u> To support development of new types of rehabilitation manpower and new training techniques		-1.,2.,3.,4.,5. Clinical, teaching, administration, supervision
3. <u>State Vocational Rehabilitation Agency In-Service Training Projects</u> To expand and improve state rehabilitation services by supporting training of state agency staff		-1. Masters or doctorate in rehabilitation nursing, counseling, or social work; or in physical therapy, occupational therapy 2.,3. Non-degree, Masters, or doctorate 4.,5. Non-degree
4. <u>Rehabilitation Continuing Education Programs</u> To support training for both new and experienced staff at state and closely related private rehabilitation agencies		
5. <u>Short-Term Training Projects of National or Regional Scope</u> To support special seminars, institutes, workshops, etc. that train rehabilitation personnel in techniques of service delivery		
<u>Traineeships for Students in Other Graduate Programs</u> (PL 94-484; expires 9/30/80) To support students in graduate accredited health administration programs	DHEW/PHS/HRA/BHM/ Division of Associated Health Professions/Education Development Branch	-Baccalaureate -Administration -Masters or doctorate in health or hospital administration or health policy analysis and planning
<u>Traineeships for Students in Schools of Public Health and Other Graduate Public Health Programs</u> (PL 94-484; expires 9/30/80) Traineeships for students in graduate education	DHEW/PHS/HRA/BHM/ Division of Associated Health Professions/Education Development Branch	-Baccalaureate -Administration -Masters or doctorate in biostatistics or epidemiology; health administration or health planning; environmental or occupational health; dietetics or nutrition; maternal and child health

TABLE 1. FEDERAL FUNDING FOR NURSES AND ALLIED HEALTH PROFESSIONALS

Name of Program (Legislative Authority) Objective	Agency	-Prerequisites -Type of Training -Award Conferred
TRAINEESHIPS (continued)		
Maternal and Child Health Training; (Social Security Act, Title V, and PL 89-97 as amended; continuing) To provide health care and serv- ices to mothers and children, par- ticularly mentally retarded and multiply handicapped children	DHEW/HSA/BCHS/ Office for Maternal and Child Health/ Research and Training Services Branch	-For Masters and higher: baccalaureate in nursing, nutrition, occupational therapy, physical therapy, or social work; baccalaureate in another discipline acceptable in rare cases. For non-degree training: no educational or disciplinary requirements (*RNs without baccalaureate would qualify) -Clinical, teaching, adminis- tration -Non-degree workshops, Masters, doctorate, or postdoctorate in all of above specialties plus public health
WORK STUDY		
College Work Study Program (PL 89-329, PL 92-318, PL 94-482 PL 95-566; expires 9/30/83) Part-time employment of students with great financial need	DHEW/OE/BSFA/Div!- sion of Policy and Program Development/ Campus-Based Grant Branch	-Financial need must be estab- lished -Undergraduate, graduate, and vocational -Non-degree, Masters, or doctorate

TABLE 2. FEDERAL FUNDING FOR NURSES

Name of Program (Legislative Authority) Objective	Agency	-Prerequisites -Type of Training -Award Conferred
GRANTS		
<u>Army Nurse Corps Program</u> (not applicable) To provide for advanced nursing training	Dept. of the Army/ Army Nurse Corps Career Activities Office	-Must be active duty Army Nurse Corps officer -Administration, clinical -Masters in nursing
<u>Occupational Safety and Health Training Grants</u> PL 78-410, PL 91-586; continuing) To develop personnel trained in occupational medicine, occupational health nursing, industrial hygiene and safety	DHEW/PHS/Center for Disease Con- trol/National In- stitute for Occu- pational Safety and Health	-Information not available -Clinical, teaching -Non-degree, Masters, or doctorate
<u>National Research Service Awards (NRSA)</u> - Individual Nurse Fellowships and Institutional Awards (PL 95-622; expires 9/30/81) To prepare nurses for research and graduate faculty roles	DHEW/PHS/HRA/ BHM/Division of Nursing/Research Training Section	-Doctorate for individ- ual NRSA; baccalaureate and/or Masters in nursing for institutional NRSA -Research, teaching -Masters or doctorate
TRAINEESHIPS		
<u>Nurse Practitioner Traineeships</u> (PL 96-76; expires 9/30/80) To educate registered nurses who will be qualified to provide primary health care	DHEW/PHS/HRA/BHM/ Division of Nursing	-Baccalaureate Applicants must come from health manpower shortage area and enter a commitment to practice as a nurse practitioner in a health manpower shortage area -Clinical -Masters in university programs; non-degree continuing education programs at other institutions
<u>Professional Nurse Traineeships</u> (PL 96-76; expires 9/30/80) To prepare registered nurses for positions requiring advanced training	DHEW/PHS/HRA/BHM/ Division of Nursing	-Baccalaureate from State-approved nursing school -Administration, supervision, teaching, clinical -Masters or doctorate

TABLE 3. FEDERAL FUNDING FOR ALLIED HEALTH PROFESSIONALS

<u>Name of Program</u> (Legislative Authority) <u>Objective</u>	<u>Agency</u>	<u>Prerequisites</u> <u>Type of Training</u> <u>Award Conferred</u>
GRANTS		
<u>Army Medical Department Program</u> (not applicable) To provide for advanced training of certain allied health professionals	Dept. of the Army/Army Medical Dept.	-Dietitians, occupational therapists, physical therapists -Administration, clinical -Non-degree in dietetics and occupational therapy; Masters in physical therapy
<u>Medical Service Corps Program</u> (not applicable) To provide for advanced training of certain allied health professionals	Dept. of the Army/Medical Service Corps	-Health educators, pharmacists, and social workers who are active duty Army officers -Non-degree, 2-year, inservice program for social workers for whom Masters is required for entry into active duty; Masters in hospital administration or doctorate in education for health educators; Masters in hospital pharmacy for pharmacists
LOANS		
<u>Health Education Assistance Loans</u> (PL 94-484; expires 9/30/80) To authorize educational loans from eligible lenders	DHEW/OE/BSFA/ Division of Policy and Program Development/Health Loan Branch	-Three years of training in pharmacy; baccalaureate in other field -Clinical -Bachelor or Master of Science equivalent in pharmacy; graduate or equivalent degree in public health
TRAINEESHIPS		
<u>Allied Health Traineeship Grants for Advanced Training (Long-Term)</u> (PL 94-484; expires 9/30/80) To support traineeships enabling AHPs to become teachers, administrators, and supervisors in allied health	DHEW/PHS/HRA/BHM/ Division of Associated Health Professions/Education Development Branch	-Dietitians, occupational therapists, physical therapists -Teaching, administration, supervision -Masters or doctorate
<u>Allied Health Traineeship Grants for Advanced Training Institutes (Short-Term)</u> (PL 94-484; expires 9/30/80) To support traineeships for study of teaching, administration, or supervision in allied health	DHEW/PHS/HRA/BHM/ Division of Associated Health Professions/Education Development Branch	-Dietitians, occupational therapists, physical therapists -Teaching, administration, supervision -Non-degree: advanced training, inservice training, continuing education

TABLE 4. FEDERAL FUNDING FOR EDUCATIONAL PROGRAM SUPPORT

Name of Program (Legislative Authority) Objective	Agency	-Eligibility -Objective
FORMULA GRANTS		
<u>Graduate Programs in Health Administration (PL 94-484, Section 791; expires 9/30/80)</u>	DHEW/PHS/HRA/ Bureau of Health Manpower	-Accredited public or nonprofit private educa- tional entity (excluding schools of public health) which offers a program in health administration, hospital administration, or health planning -To support graduate pro- grams in the above fields
<u>Health Professions - Capitation Grants (PL 94-484, Section 101k; expires 9/30/80)</u>	DHEW/PHS/HRA/ Bureau of Health Manpower	-Schools of pharmacy, public health, and other medical disciplines -To provide assistance to schools in return for ad- dressing geographic, spec- ialty, and enrollment goals; funds may not be used for construction or financial assistance to students
PROJECT GRANTS		
<u>National Institute of Handicapped Research (PL 95-602; expires 9/30/82)</u>	DHEW/OHDS/National Institute for Rehab- ilitation Research	-States, public or private nonprofit agencies and or- ganizations, including in- stitutions of higher educa- tion -To support research and its utilization through identify- ing and eliminating causes and consequences of disability; maximizing physical and emotional status of handicap persons; preventing or min- imizing effects of disability; reducing and eliminating bar- riers of accessibility

TABLE 4. FEDERAL FUNDING FOR EDUCATIONAL PROGRAM SUPPORT

Name of Program (Legislative Authority) Objective	Agency	-Eligibility -Objective
PROJECT GRANTS (continued)		
Rehabilitation Services Administration Programs (PL 93-112, PL 94-230, PL 95-602; expires 9/30/82)		
1. <u>Long-Term Training Grants</u>	DHEW/OHDS/RSA/ Division of Man- power Development (Same as above for all five programs)	-1. Graduate schools accredited in specific rehabilitation disciplines
2. <u>Experimental and Innovative Training Projects</u>		2,4,5. Institutions of higher education, and nonprofit public or private rehabili- tation agencies
3. <u>State Vocational Rehabilitation Agency In-Service Training Projects</u>		3. State vocational rehabilita- tion agencies
4. <u>Rehabilitation Continuing Edu- cation Programs</u>		-1. To support basic or advanced professional training in reha- bilitation
5. <u>Short-Term Training Projects of National or Regional Scope</u>		2. To support development of new types of rehabilitation man- power and new training tech- niques 3. To expand and improve state rehabilitation services by supporting training of state agency staff 4. To support training for both new and experienced staff at state and closely related private rehabilitation agencies 5. To support special seminars, institutes, workshops, etc. that train rehabilitation personnel in techniques of service delivery
<u>Mental Health Clinical or Service Related Training Grants</u> (PL 78-410; continuing)	DHEW/PHS/ ADAMHA/NIMH/ Division of Manpower and Training Pro- grams	-Public or private non- profit institutions and organizations, and state and local government agencies -To maintain and develop programs in mental health training and manpower
<u>Allied Health Professions Project Grants</u> (PL 94-484, Section 796; expires 9/30/80)	DHEW/PHS/ HRA/Bureau of Health Manpower	-Any public or nonprofit private entities capable of carrying out relevant projects -To establish or improve recruit- ment, training, and retraining of allied health personnel
<u>Health Careers Opportunity Program</u> (PL 94-484, Section 798 for Allied Health Pro- fessions; expires 9/30/80)	DHEW/PHS/ HRA/Bureau of Health Manpower	-Schools of allied health, state and local educational agencies, and other public or private nonprofit entities -To identify and select individuals of disad- vantaged backgrounds to enter allied health professions

TABLE 4. FEDERAL FUNDING FOR EDUCATIONAL PROGRAM SUPPORT

Name of Program (Legislative Authority) Objective	Agency	-Eligibility -Objective
PROJECT GRANTS (continued)		
<u>Health Professions - Financial Distress Grants (PL 94-484, Section 788a; expires 9/30/80)</u>	DHEW/PHS/ HRA/Bureau of Health Manpower	-Schools of pharmacy, public health, and other medical disciplines -To assist schools in finan- cial distress to meet costs and accreditation require- ments and make administrative reforms
<u>Health Professions - Start-Up Assistance (Sections 215 and 788(a) of Public Health Service Act; expires 9/30/80)</u>	DHEW/PHS/ HRA/Bureau of Health Manpower	-Schools of pharmacy, public health, and other medical disciplines -To assist new schools to accelerate start of instruc- tion or increase enrollment
<u>Public Health Special Project Grants (PL 94-484, Section 792; expires 9/30/80)</u>	DHEW/PHS HRA/Bureau of Health Manpower	-Schools of public health with graduate programs preparing individuals in biostatistics or epidemi- ology; health planning, health administration, or health policy analysis and planning; environmental or occupational health; die- tetics or nutrition -To strengthen or expand graduate public health programs
<u>Curriculum Development Grants (PL 94-484, Section 788d; ex- pires 9/30/80)</u>	DHEW/PHS/HRA/ Division of Associated Health Profes- sions/Interdis- ciplinary Programs Branch and DHEW/PHS/HRA Division of Medicine/Multi- disciplinary Pro- grams Section	-Any health profession, allied health profession, or nurse training insti- tution, or any other public or private non- profit entity -To assist schools to develop and implement new course materials in applied nutrition, environmental health, or geriatrics. Geri- atric program specifies the importance of multidisciplinary care and course materials which address care for aged pa- tients with disabilities that restrict mobility
<u>Area Health Education Centers (PL 94-484; expires 9/30/80)</u>	DHEW/PHS/HRA/ BHM/Division of Medicine	-Accredited public or nonprofit schools of medicine or osteo- pathy. These schools establish Allied Health Education Centers and the Centers subcontract with allied health professions and nursing schools to provide training -To improve distribution, supply, quality, utilization of health personnel and increase regional ization of responsibilities of health professions schools

TABLE 4. FEDERAL FUNDING FOR EDUCATIONAL PROGRAM SUPPORT

<u>Name of Program</u> (Legislative Authority) <u>Objective</u>	<u>Agency</u>	<u>-Eligibility</u> <u>-Objective</u>
PROJECT GRANTS (continued)		
<u>Advanced Nurse Training Program</u> (PL 96-76; expires 9/30/80)	DHEW/PHS/HRA/ BHM/Division of Nursing	-Public and nonprofit private accredited schools of nursing -To meet program costs to plan, develop, and operate new pro- grams for advanced training of RNs as administrators, supervisors, educators, or clinicians in one or more of the following nursing areas: maternal-child health, community health, geriatric, adult, medi- cal-surgical, or acute care
<u>Nurse Practitioner Training Program</u> (PL 96-76; expires 9/30/80)	DHEW/PHS/ HRA/BHM/ Division of Nursing	-State and local government; public or nonprofit private schools of nursing, medicine, and public health; public or nonprofit private hospitals; other public or nonprofit private entities -To meet costs of projects to maintain or expand pro- grams to train nurse practitioners
<u>Nurse Training Improvement - Special Projects</u> (PL 96-76; expires 9/30/80)	DHEW/PHS/ HRA/BHM/ Division of Nursing	-Public and nonprofit private schools of nursing and other public or nonprofit private entities -To fund projects designed to improve the quality and avail- ability of nursing education
<u>Nursing Capitation Grants</u> (PL 96-76; expires 9/30/80)	DHEW/PHS/ HRA/BHM/ Division of Nursing	-Public or nonprofit school of nursing -To support educational programs of nursing schools
<u>Nursing Research Project Grants</u> (PL 78-410; continuing)	DHEW/PHS/ HRA/BHM/ Division of Nursing	-Nonprofit organization or in- stitution, or government agen- cy; grants occasionally awarded to individuals -To support basic and applied re- search activities in nursing ed- ucation, practice, and adminis- tration
<u>Crippled Children's Services</u> (PL 74-271; continuing)	DHEW/PHS/HSA/ BCHS/Office for Maternal and Child Health	-State crippled children's agen- cies and institutions of higher learning -To provide support for special projects, including training, of regional or national significance which may advance services for crippled children

TABLE 4. FEDERAL FUNDING FOR EDUCATIONAL PROGRAM SUPPORT

Name of Program (Legislative Authority) Objective	Agency	-Eligibility -Objective
PROJECT GRANTS (continued)		
<u>Biomedical Research Support - Bio- medical Research Support Grants (BRSG) and Biomedical Research Development Grants (BRDG) (PL 78-410; continuing)</u>	DHEW/PHS/ NIH/Division of Research Resources	-For BRSG: institutions must receive a minimum of \$200,000 in PHS research grants during preceding fiscal year; for BRDG: institutions receiving less than \$200,000 -For BRSG: to strengthen, balance and stabilize PHS supported biomedical and behavioral research innovations; for BRDG: to strengthen health-related research in institutions providing professional training for clinical and health research
<u>Grants to Assist in the Education and Training of Professional and Technical Allied Health Manpower (PL 92-541, PL 96-151; 9/30/79 authorizations expired; continua- tions funded through FY 83)</u>	VA/Depart- ment of Medicine and Surgery/Office of Academic Affairs	-Nonprofit educational facilities, other public or nonprofit institutions, or consortium of such institutions affiliated with a VA medical facility; Special consideration for programs giving priority admission to qualified veterans -To coordinate, improve, and expand education and training programs for AHPs; to improve and expand health manpower utilization; to broaden availability of AHP continuing education programs

ACRONYMS

ADAAHA	- Alcohol, Drug Abuse, and Mental Health Administration
AHP	- Allied Health Professional
AOA	- Administration on Aging
BCHS	- Bureau of Community Health Services
BHM	- Bureau of Health Manpower
BRDG	- Biomedical Research Development Grants
BRSG	- Biomedical Research Support Grants
BSFA	- Bureau of Student Financial Assistance
CAA	- Community Action Agency
CDC	- Center for Disease Control
CETA	- Comprehensive Employment and Training Administration
CFDA	- Catalog of Federal Domestic Assistance
CSA	- Community Services Administration
DHEW	- Department of Health, Education, and Welfare
DHHS	- Department of Health and Human Services
DMTS	- Division of Manpower Training and Support
DN	- Division of Nursing
ED	- Department of Education
E-W	- East-West (Highway)
FY	- Fiscal Year
GCRC	- General Clinical Research Center
HCFA	- Health Care Financing Administration
HRA	- Health Resources Administration
HSA	- Health Services Administration
HUD	- Housing and Urban Development (Department of)
NIA	- National Institute on Aging
NIAID	- National Institute of Allergy and Infectious Diseases
NIAMDD	- National Institute of Arthritis, Metabolism, and Digestive Diseases
NICHD	- National Institute of Child Health and Human Development
NIE	- National Institute of Education
NIGMS	- National Institute of General Medical Sciences
NIH	- National Institutes of Health
NIMH	- National Institute of Mental Health
NINCDS	- National Institute of Neurological and Communicative Disorders and Stroke
NIOSH	- National Institute of Occupational Safety and Health
NRSA	- National Research Service Award
NSF	- National Science Foundation
OE	- Office of Education
OHDS	- Office of Human Development Services
OMCH	- Office for Maternal and Child Health
PHS	- Public Health Service
PL	- Public Law
RCU	- Research Coordination Unit
RN	- Registered Nurse
RSA	- Rehabilitation Services Administration
SSA	- Social Security Administration
VA	- Veterans Administration

APPENDIX C

FEDERALLY LEGISLATED RESEARCH SUPPORT FOR NURSES
AND ALLIED HEALTH PROFESSIONALS

Federally Legislated Research Support for Nurses
and Allied Health Professionals

INTRODUCTION

This report identifies Federal research funds available to nurses and allied health professionals who are interested in the process and treatment of rheumatic diseases. Though inflation has reduced the "real" dollars spent on research, health-related research funding has traditionally been and continues to be more stable over the years than funding for education and advanced training of health professionals.

The scope of this document is fairly wide, and the 45 Federal programs presented represent a range of research interests. Some focus directly on the biomedical and clinical aspects of rheumatic diseases, while others are concerned with the broader areas of rehabilitation and patient and professional education.

Some clarification should be made regarding the information in these tables. First, the information gathered is as current as possible. Nevertheless, as Federal programs must be responsive to changing needs, it is conceivable that some of the entries may be outdated by the time the report is printed.

Second, even though individuals may technically be eligible, as noted in the tables, to receive support for several of the programs presented, most funds are awarded to institutions and organizations to support research performed by a named investigator or staff of investigators. Discussions with Federal program administrators about eligibility for project investigators revealed no disciplinary or educational restrictions. However, the decision to fund an application is usually based on a review of its merits relative to other applications. The qualifications and experience of the proposed researcher(s) are always an important consideration. While physicians have historically received much of the Federal health-related research money, no legal or official barriers prevent nurses and allied health professionals from applying for or receiving this funding.

As competition for funding grows stiffer, a combination of factors--quality education, advanced training, and related experience--will aid increasing numbers of nurses and allied health professionals to receive a larger portion of the Federal research dollar.

NOTE: This appendix represents an abbreviated version of a report compiled by the Arthritis Information Clearinghouse. To receive the complete report, which contains further information about each Federal funding program presented in this appendix, contact the Clearinghouse at:

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FEDERALLY LEGISLATED RESEARCH SUPPORT FOR NURSES
AND ALLIED HEALTH PROFESSIONALS

Name of Program (Legislative Authority) Objectives	Agency	-Type of Assistance -Eligibility
<u>13.103 Food and Drug Administration</u> <u>- Research</u> (PL 78-410; continuing) To establish, expand, and improve research activities concerned with foods, food additives, shellfish sanitation, poison control, drug and cosmetic hazards, human and veterinary drugs, medical devices and diagnostic products, biologics, and radiation-emitting devices and materials	DHHS/PHS/Food and Drug Administration	-Project grants (contracts) -Colleges, universities, non-profit institutions, state and local governments, and individuals may apply for support of costs directly related to the research performed
<u>13.211 Crippled Children's Services</u> (Social Security Act and Amendments; continuing) Special projects of regional or national significance which may contribute to the advancement of services for crippled children. Current special interests include adolescents, habilitation of handicapped children, and counseling and informed consent.	DHHS/PHS/Health Services Administration	-Formula grants, project grants -Formula and project grants available to state crippled children's agencies. Project grants also available to institutions of higher learning. Grants are not available to individuals.
<u>13.226 Health Services Research and Development - Grants to State Agencies</u> (PL 93-353 as amended by PL 95-623; September 30, 1981) Studies supported in ten areas of concern: (1) cost containment; (2) health insurance; (3) planning and regulation; (4) technology and computer science applications; (5) health manpower; (6) long-term care; (7) quality of care; (8) health care and the disadvantaged; (9) emergency medical services and ambulatory care; and (10) special studies	DHHS/PHS/Office of the Assistant Secretary for Health	-Project grants -States, counties, cities, towns, political subdivisions, universities, colleges, hospitals, U.S. Territories, Native Americans, and other public or nonprofit private agencies, institutions, or organizations; individuals may also receive research project grants
<u>13.231 Maternal and Child Health Research</u> (PL 86-778; continuing) To provide research projects relating to maternal and child health services or crippled children's services which show promise of substantial contribution to the advancement of such services. Research is applied, not basic, in such areas as: health care delivery, habilitation and rehabilitation of handicapped children, regionalization of services, and manpower.	DHHS/PHS/Health Services Administration	-Project grants -Grants may be made to public or other nonprofit institutions of higher learning and to public or other nonprofit agencies including state and local governments and organizations engaged in research or in maternal and child health or crippled children's programs. Grants cannot be awarded to individuals.

FEDERALLY LEGISLATED RESEARCH SUPPORT

Name of Program (Legislative Authority) Objectives	Agency	-Type of Assistance -Eligibility
<u>13.242 Mental Health Research Grants</u> (PL 78-410; continuing) To develop new knowledge, approaches, and models of service delivery in mental health, usually through interdisciplinary research and related collaborative research activities. To support research in such areas as: aging and child mental health, epidemiology, metropolitan and minority mental health problems, and other social problems. One of the research programs, entitled "Small Grants," supports development and testing of new techniques; exploratory studies; and unexpected research opportunities.	DHHS/PHS/Alcohol, Drug Abuse, and Mental Health Administration	-Project grants (cooperative agreements) -Investigators affiliated with public or nonprofit private agencies, including state, local, or regional government agencies, universities, colleges, hospitals, academic or research institutions, other organizations, and individuals. Small grants are primarily intended for the newer, less experienced investigator and others who do not have regular research support or resources available from their institutions.
<u>13.262 Occupational Safety and Health Research Grants</u> (PL 78-410, PL 91-596, PL 95-164; continuing) To understand the underlying characteristics of occupational safety and health problems and for effective solutions in dealing with them. To eliminate or control factors in the work environment which are harmful to the health and/or safety of workers. To demonstrate technical feasibility or application of a new or improved occupational safety and health procedure, method, technique, or system	DHHS/PHS/Center for Disease Control	-Project grants -Any individual state or local government, nonprofit organization, state college or university or public, private, junior, or community college capable of conducting research in the field of occupational safety and/or health
<u>13.333 Clinical Research</u> (PL 78-410; continuing) To create General Clinical Research Centers (GCRC) as resources where clinical investigators may study human disease. To support multiple projects in various research areas such as nutrition, diabetes, growth and development, genetics studies, immunology, and others	DHHS/PHS/NIH/Division of Research Resources	-Project grants -Public or nonprofit private medical schools, research hospitals, and other medical institutions are eligible to apply for funds to establish a GCRC. Researchers affiliated with an institution running one of the 75 GCRCs can submit a protocol and be granted use of GCRC facilities and in some cases funding support.
<u>13.361 Nursing Research Project Grants</u> (PL 78-410; continuing) To pursue basic and applied research activities in nursing education, practice, and administration	DHHS/PHS/Health Resources Administration	-Project grants -Nonprofit organization or institution, or government agency; grants occasionally awarded to individuals. No disciplinary requirements for researchers.

FEDERALLY LEGISLATED RESEARCH SUPPORT

Name of Program (Legislative Authority) Objectives	Agency	-Type of Assistance -Eligibility
<u>13.375 Minority Biomedical Support</u> (PL 78-410; continuing) To broaden the opportunities for participation in biomedical research of ethnic minority faculty, students, and investigators by providing support for biomedical research programs at eligible institutions	DHHS/PHS/NIH/Division of Research Resources	-Project grants -Four-year colleges, universities, and health professional schools with over 50 percent minority enrollment; four-year institutions with significant but not necessarily over 50 percent minority enrollment, provided they have a history of encouragement and assistance to minorities; two-year colleges with 50 percent minority enrollment; Indian tribal school which has recognized governing body and which performs substantial government functions; or an Alaska Regional Corporation as defined in the Alaska Native Claims Settlement Act; no grants to individuals
<u>13.443 Handicapped - Research and Demonstration</u> (PL 91-230 as amended by PL 95-49; September 30, 1982) To improve the education of handicapped children through research and development projects and model programs	ED/Office of Special Education and Rehabilitative Services	-Project grants (contracts) -State or local educational agencies, public and private institutions of higher learning, and other public or private educational or research agencies and organizations may apply. No disciplinary restrictions for researchers at these institutions.
<u>13.444 Handicapped Early Childhood Assistance</u> (PL 91-230 as amended by PL 95-49; September 30, 1982) To support experimental demonstrations in the following priority areas: entry of handicapped children into the regular school system; improved delivery of specialized services to handicapped children residing in rural areas and those who are economically disadvantaged; service to children with specific handicapping conditions	ED/Office of Special Education and Rehabilitative Services	-Project grants -Public agencies and private nonprofit organizations. Health professionals are eligible to be included in the organization's proposed staffing pattern.
<u>13.475 Library Research and Demonstration</u> (PL 92-318; continuing) To improve libraries and information science practices through research and demonstration projects in specialized services, including health information services	ED/Office of Libraries and Learning Technologies	-Project grants (contracts) -Grants awarded to all institutions of higher education and other public or private agencies, institutions, and organizations of a nonprofit nature; contracts awarded only to profit-making agencies and organizations. No disciplinary restrictions for researchers at these institutions.

FEDERALLY LEGISLATED RESEARCH SUPPORT

Name of Program (Legislative Authority) Objectives	Agency	-Type of Assistance -Eligibility
<u>13.495 Vocational Education - Program Improvement and Supportive Service</u> (PL 94-482; September 30, 1982, with automatic one-year extension) Funds support state Research Coordination Units (RCU). RCUs direct research contracts for innovative vocational education programs and curriculum development programs.	ED/Division of State Vocational Programs	-Formula grants -State Boards for Vocational Education receive RCU funds. RCUs contract for research with institutions. No disciplinary restrictions for researchers at these institutions.
<u>13.564 Consumers' Education</u> (PL 95-561; September 30, 1983) To provide consumers' education to students and the general public by researching, developing, pilot testing, and disseminating curricula and other activities and materials and by establishing or expanding pilot or demonstration projects to serve the needs of special groups including the handicapped	ED/Office of School Improvement	-Project grants, contracts -Institutions of higher education, state and local educational agencies, and other public and private nonprofit agencies, organizations, and institutions (including libraries)
<u>13.631 Developmental Disabilities - Special Projects</u> (PL 88-164 as amended by PL 95-602; continuing) To support projects to improve quality of services to the developmentally disabled; public awareness and informational programs; demonstration of new or improved service techniques and service delivery	DHHS/Office of Human Development Services	-Project grants -States, political subdivisions of states, other public agencies, and nonprofit organizations. State of applicant must have approved state plan under Mental Retardation Facilities and Community Mental Health Centers Construction Act.
<u>13.634 Special Programs for the Aging - Discretionary Projects and Programs</u> (PL 89-73 as amended by PL 95-478; September 30, 1981) To demonstrate new approaches, techniques, and methods to improve or expand social services or nutrition services or otherwise promote the well-being of older individuals. Projects include study of home health services, housing for the elderly with physical disabilities, and coordination of social services to homebound disabled elderly.	DHHS/Office of Human Development Services	-Project grants (contracts) -Any public or private nonprofit agency, institution, or organization engaged in activities related to serving the needs of older people or the field of aging. Grants are not available to individuals, even though they may be affiliated with a public or nonprofit organization. Contracts for specific purposes may be made with any public or private agency, organization, or with any individual.
<u>13.636 Special Programs for the Aging - Research and Development</u> (PL 89-731 as amended by PL 95-478, September 30, 1981) To develop knowledge of the needs and conditions of older persons and of policies, programs, and services for improving their lives	DHHS/Office of Human Development Services	-Project grants, contracts -Grants to any public or nonprofit agency, organization, or institution; contracts to any agency, organization, institution, or individual

FEDERALLY LEGISLATED RESEARCH SUPPORT

Name of Program (Legislative Authority) Objectives	Agency	-Type of Assistance -Eligibility
<u>13.647 Social Services Research and Demonstration</u> (Social Security Act and Amendments; continuing) To pursue new social service concepts which will provide service to dependent and vulnerable populations such as the poor, aged, children, Native Americans, and the handicapped	DHHS/Office of Human Development Services	-Project grants, cooperative agreements, contracts -Grants and cooperative agreements may be made to or with states and nonprofit organizations. Contracts may be executed with nonprofit or profit organizations. Grants or cooperative agreements cannot be made directly to individuals.
<u>13.649 Rehabilitation Services and Facilities - Innovation and Expansion</u> (PL 95-602; September 30, 1982) To provide part of the cost of planning, preparing for, and initiating special programs under the state plan in order to expand and improve vocational rehabilitation services for the the mentally and physically handicapped	DHHS/Office of Human Development Services	-Formula grants -State and/or local agency. State agency may award funds to a public or nonprofit organization or agency.
<u>13.654 National Institute of Handicapped Research</u> (PL 93-112 as amended by PL 95-602; September 30, 1982) To improve the lives of people of all ages with physical and mental handicaps, especially the severely disabled, through: identifying and eliminating causes and consequences of disability; maximizing functional ability of handicapped persons; preventing or minimizing personal and family effects of disability; reducing and eliminating barriers to access to services and employment	ED/Office of Special Education and Rehabilitative Services	-Project grants (cooperative agreements), contracts -Grants, cooperative agreements, and contracts may be made to or with states, public or private nonprofit agencies and organizations, including institutions of higher education; individuals may not receive funding.
<u>13.680 Telecommunications Demonstrations for Health, Education, and Other Social Services</u> (PL 95-567; September 30, 1981) To promote development of nonbroadcast telecommunications facilities and services for the transmission, distribution, and delivery of health, education, and social service information	ED/Office of Libraries and Learning Technologies	-Project grants (contracts) -Public or private nonprofit agencies, organizations, and institutions, including state and local governments

FEDERALLY LEGISLATED RESEARCH SUPPORT

Name of Program (Legislative Authority) Objectives	Agency	-Type of Assistance -Eligibility
<u>13.766 Health Financing Research, Demonstrations, and Experiments</u> (Social Security Act and amendments, continuing) To discover, test, demonstrate, and promote utilization of financing concepts which will provide service to beneficiary population while at the same time providing incentives for efficient use of services/resources by provider and beneficiaries. Areas of interest include: child health, health systems organization, integrated data systems, and long-term care.	DHHS/Health Care Financing Administration	-Project grants, contracts -States and nonprofit organizations. Grants cannot be made directly to individuals.
<u>13.812 Assistance Payments - Research</u> (Social Security Act and Amendments; continuing) To experiment, pilot, demonstrate, and research new public assistance concepts to reduce dependency, and to improve living conditions of recipients of public assistance. To develop more knowledge on the characteristics and financial needs of a target group	DHHS/Social Security Administration	-Project grants, contracts -Grants may be made to states and nonprofit organizations, not to individuals. Contracts may be executed with nonprofit or profit-making organizations.
<u>13.821 Physiology and Biomedical Engineering</u> (PL 78-410; continuing) To investigate application of concepts from mathematics, physics, and engineering to biological systems; use of engineering principles in development of computers for patient monitoring; and/or any areas of research related to physiology, anesthesiology, trauma, and burn studies, and related areas. Fundamental research in area of biomaterials is of interest.	DHHS/PHS/NIH/National Institute of General Medical Sciences	-Project grants -Any public or private nonprofit university, college, hospital, laboratory, or other institution including states and local units of government, or to any individual
<u>13.846 Arthritis, Bone, and Skin Diseases Research</u> (PL 78-410; continuing) To support basic laboratory research and clinical investigations	DHHS/PHS/NIH/National Institute of Arthritis, Metabolism, and Digestive Diseases	-Project grants -Individuals and public and nonprofit institutions proposing to establish, expand, and improve research activities in health sciences and related fields
<u>13.847 Diabetes, Endocrinology and Metabolism Research</u> (PL 78-410; continuing) To support basic laboratory research and clinical investigations	DHHS/PHS/NIH/National Institutes of Arthritis, Metabolism, and Digestive Diseases	-Project grants -Individuals and public nonprofit institutions proposing to establish, expand, and improve research activities in health sciences and related fields

FEDERALLY LEGISLATED RESEARCH SUPPORT

Name of Program (Legislative Authority) Objectives	Agency	-Type of Assistance -Eligibility
<u>13.848 Digestive Diseases and Nutrition Research</u> (PL 78-410; continuing) To support basic laboratory research and clinical investigations	DHHS/PHS/NIH/National Institute of Arthritis, Metabolism, and Digestive Diseases	-Project grants -Individuals and public and nonprofit institutions proposing to establish, expand, and improve research activities in health sciences and related fields
<u>13.854 Fundamental Neurosciences Research</u> (PL 78-410; continuing) To elucidate the mechanism responsible for normal function of the human nervous system and to understand the nature of its diseases and disorders	DHHS/PHS/NIH/National Institute of Neurological and Communicative Disorders and Stroke	-Project grants -Any public or private nonprofit institution and individuals
<u>13.855 Pharmacological Sciences</u> (PL 78-410; continuing) To establish, expand, and improve biomedical research in allergic diseases and related areas. To assist public, private, and commercial institutions to conduct developmental research, to produce and test research materials, and provide research services as required by the agency in allergic and immunologic diseases	DHHS/PHS/NIH National Institute of Allergy and Infectious Diseases	-Project grants -Universities, colleges, hospitals, laboratories, and other public or private nonprofit domestic institutions including state and local units of government, and individuals
<u>13.856 Microbiology and Infectious Diseases Research</u> (PL 78-410; continuing) To establish, expand and improve biomedical research in infectious diseases and related areas	DHHS/PHS/NIH/National Institute of Allergy and Infectious Diseases	-Project grants -Universities, colleges, hospitals, laboratories, and other public or private nonprofit domestic institutions including state and local units of government, and individuals
<u>13.859 Pharmacology - Toxicology Research</u> (PL 78-410; continuing) To improve medical therapy through acquisition of increased knowledge of the mechanisms of drug action and of ways to increase efficacy and safety, and to diminish toxicity	DHHS/PHS/NIH/National Institute of General Medical Sciences	-Project grants -Any public or private nonprofit university, college, hospital, laboratory, or other institutions, including state and local units of government, or any individual
<u>13.862 Genetics Research</u> (PL 78-410; continuing) To investigate prevention, therapy, and control of genetic diseases in humans, including those multifactorial illnesses with a strong hereditary component	DHHS/PHS/NIH/National Institute of General Medical Sciences	-Project grants -Any public or private nonprofit university, college, hospital, laboratory, or other institutions, including state and local units of government, or any individual

FEDERALLY LEGISLATED RESEARCH SUPPORT

Name of Program (Legislative Authority) Objectives	Agency	-Type of Assistance -Eligibility
<u>13.863 Cellular and Molecular Basis of Disease Research</u> (PL 78-410; continuing) To investigate the structure and function of cells and their component parts, with the expectation that a greater understanding of these aspects will contribute to ultimate control of all forms and manifestations of human disease	DHHS/PHS/NIH/National Institute of General Medical Sciences	-Project grants -Any public or private non-profit university, college, hospital, laboratory, or other institutions, including state and local units of government, or any individual
<u>13.865 Research for Mothers and Children</u> (PL 78-410; continuing) To improve the health and well-being of mothers, children, and families as the key to ensuring a healthy adult population. To study health problems of the period of life from conception through adolescence, centering on the major problems of pregnancy and infancy, developmental biology and nutrition, human learning and behavior, and mental retardation and developmental disabilities	DHHS/PHS/NIH/National Institute of Child Health and Human Development	-Project grants -Universities; colleges; medical, dental, and nursing schools; schools of public health; laboratories; hospitals; state and local health departments; and other public or private nonprofit institutions, and individuals
<u>13.866 Aging Research</u> (PL 78-410; continuing) To pursue biomedical, social, and behavioral research directed toward greater understanding of the aging process and the needs and problems of the elderly. To improve the health and well-being of the elderly through the development and application of new knowledge	DHHS/PHS/NIH/National Institute on Aging	-Project grants -Universities; colleges; medical, dental, and nursing schools; schools of public health; laboratories; hospitals; state and local health departments; other public or private nonprofit institutions, and individuals
<u>13.879 Medical Library Assistance</u> (PL 89-291 as amended by PL 95-622; September 30, 1981) To improve health information services by providing funds for research on improving information transfer	DHHS/PHS/NIH/National Library of Medicine	-Project grants -Public or private nonprofit institutions with research capabilities in health information fields. Grant cannot be made to profit-making institutions or to individuals.

FEDERALLY LEGISLATED RESEARCH SUPPORT

Name of Program (Legislative Authority) Objectives	Agency	-Type of Assistance -Eligibility
<u>13.950 Educational Research and Development</u> (PL 92-318 as amended by PL 96-49; September 30, 1980) To improve the quality of educational practice, to promote the national policy of providing equal educational opportunities to all persons, and to support scientific inquiry into the educational process and dissemination activities through grant awards based on projects that are most likely to contribute to new knowledge and increased understanding of the priority research areas covered by the Institute's statutory objectives.	ED/Office of Educational Research and Improvement	-Project grants, contracts -Any institution of higher education, public or private for-profit or nonprofit agency, organization, group, individual, any combination of these, state, local, intermediate education agency, or international group or agency, and especially minority and women researchers and institutions serving them
<u>14.506 General Research and Technology Activity</u> (PL 91-609 and amendments; continuing) To carry out applied research and demonstration projects of high priority and preselected by the Department to serve the needs of housing and community development groups and to improve the operations of the Department's programs	Department of Housing and Urban Development/ Office of Policy Development and Research	-Project grants (cooperative agreements, contracts) -State and local governments, public and/or private profit and nonprofit organizations which have authority and capacity to carry out projects
<u>15.417 Urban Park and Recreation Recovery Program</u> (PL 95-625; September 30, 1983) Rehabilitation of critically needed recreation areas and facilities, development of improved recreation programs, and testing innovative delivery of recreation services	Department of the Interior/Heritage Conservation and Recreation Service	-Project grants -Cities and counties meeting program eligibility requirements. Jurisdictions not specified in these requirements may compete for discretionary funds. Grant funds may be passed from these local governments to community-based, private, nonprofit groups; health professionals would be eligible to conduct innovation projects under the auspices of these private groups.
<u>17.233 Employment and Training Research and Development Projects</u> (CETA Act of 1973 as amended by PL 95-524; September 30, 1982) To develop new approaches to facilitate employment of the difficult to employ and to conduct research and development addressing the employment implications of long-term social and economic trends and forces. To develop information on employment barriers and to test methods of helping persons on public assistance to get nonfederally assisted jobs	Department of Labor/ Employment and Training Administration	-Project grants, contracts -State colleges and universities; public, private, junior, and community colleges; state and local government organizations including U.S. Territories; and other organizations and individuals capable of fulfilling the objectives of the programs. There are no formal guidelines or conditions performers must meet other than that they have demonstrated financial responsibility and competence to fulfill the terms of the contract or grant.

FEDERALLY LEGISLATED RESEARCH SUPPORT

Name of Program (Legislative Authority) Objectives	Agency	-Type of Assistance -Eligibility
<u>47.041 Engineering and Applied Science</u> (PL 81-507; continuing) To strengthen the U.S. engineering and applied science research base and enhance the links between research and applications in meeting national goals. Included among the areas of research are science and technology to aid the handicapped.	National Science Foundation	-Project grants -Public and private colleges and universities, nonprofit institutions, state and local governments, profit-making institutions including small businesses, and agencies. Most support to academic institutions; grants occasionally made to individuals.
<u>47.054 Industry/University Cooperative Research</u> (PL 81-507; continuing) To support cooperative research projects involving both universities and industrial firms. To focus on fundamental scientific or engineering questions of basic or applied nature	National Science Foundation	-Project grants -Universities and colleges and established profit-making industrial firms, including small businesses
<u>49.010 Older Persons Opportunities and Services</u> (PL 95-568; continuing) To identify and meet the needs of poor persons above the age of 60 in projects which serve or employ older persons as the predominant or exclusive beneficiary group	Community Services Administration	-Project grants -Grants are made to Community Action Agencies (CAA), and CAAs may delegate individual projects by contract to other agencies. Grants are also made directly to state and local governments and other public and private nonprofit agencies.
<u>64.001 Biomedical Research</u> (PL 93-112; continuing) Medical research is an intramural activity conducted in VA medical centers and clinics.	Veterans Administration/ Department of Medicine and Surgery	-Use of property, facilities, and equipment -Researchers who are affiliated institutionally or otherwise with the VA. No education or disciplinary requirements for principal investigators.
<u>64.006 Rehabilitative Research - Prosthetics</u> (PL 93-112; continuing) To develop new and improved prosthetic devices, sensory aids, mobility aids, automotive adaptive equipment, and related appliances for the primary benefit of disabled veterans. Results of such research is made available to all disabled persons.	Veterans Administration/ Department of Medicine and Surgery	-Direct payments for specified use -Any institution, state or local health agency, research organization, university, or rehabilitation center

DISCRIMINATION PROHIBITED:

Under provisions of applicable public laws enacted by Congress since 1964, no person in the United States shall, on the ground of race, color, national origin, sex, or handicap, be excluded from participation in, be denied the benefits of, or be subject to discrimination under any program or activity receiving Federal financial assistance. In addition, Executive Order 11141 prohibits discrimination on the basis of age by contractors and subcontractors in the performance of Federal contracts. Therefore, the National Arthritis Advisory Board must be operated in compliance with these laws and executive order.